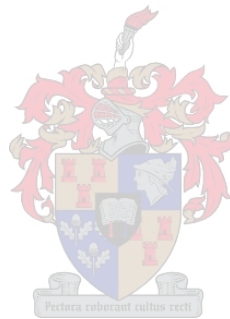


# **THE UTILISATION OF SUPPORT GROUPS FOR NON-BIOLOGICAL CAREGIVERS OF CHILDREN WITH FASD**

by

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Thesis presented in fulfilment of the requirements for the degree of  
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## **DECLARATION**

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Date: March 2015

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*“Every child deserves a champion: an adult who will never give up on them, who understands the power of connection and insists they become the best they can possibly be”.*

- Rita Pierson

*“Sometimes the things we cannot change end up changing us instead”.*

- Unknown

## ABSTRACT

Non-biological caregivers often take children into their care when their own biological caregivers have failed to provide them with a safe and loving home. These children are often also affected with Fetal Alcohol Spectrum Disorders (FASD). Learning of a child's disability can be a big shock to non-biological caregivers especially if it is misunderstood, available professional help is scarce and intervention resources are not readily available. These non-biological caregivers are often not prepared for the financial, emotional and physical investment that is required to fully support the children and their development. This can cause various emotional reactions and implications that are challenging for the caregivers.

It is critical to recognise parenting experiences and challenges as a means of developing and promoting intervention strategies and support that will respond to the needs of the children with FASD and their non-biological caregivers especially from a South African perspective. There is a need for social workers to take on responsibility for addressing FASD as they have the professional capacity to help families living with FASD to develop and maintain stable and nurturing households. One way in which this can be achieved is through the initiation and facilitation of support groups.

The goal of the study was to gain an understanding on the experiences of non-biological caregivers of children with FASD and of the utilisation of support groups to help them cope better. The researcher made use of a combination of an exploratory and descriptive research design. By using both a quantitative and qualitative approach in a complimentary manner, the researcher was able to gain an in depth insight into the lives of the non-biological caregivers and how they experience this disability and support groups that are utilised as a means of helping them cope. Permission to conduct the study was granted by the committee for Human Research at the University of Stellenbosch.

The literature study firstly investigated the implication of FASD on affected children. Secondly, the extents to which non-biological caregivers are affected by the consequences of this disability were discussed. After this the utilisation of support groups as a method of supporting non-biological caregivers, with the emphasis on a mutual-aid and educational approach as theoretical underpinning was described.

The empirical study was completed with 16 participants through face-to-face, semi-structured interviews. An interview schedule based on the findings of the literature study was utilised. The criteria for inclusion were that participants had to have attended at least 5 support group sessions and had to be a non-biological caregiver of FASD children who had attended the support groups specifically related to this disorder. The results of this study mostly confirmed the findings from the literature study which showed that support groups play a vital role in providing necessary support to non-biological caregivers who are often unprepared for the realities of caring for a FASD child.

Recommendations are aimed at the social work profession in South Africa who need to align itself in providing necessary support to non-biological caregivers through the use of support groups and various other methods of service rendering. Suggestions for future research are also made in line with how non-biological caregivers can be supported in their unique caregiver responsibilities.

## OPSOMMING

Nie-biologiese versorgers neem dikwels kinders in hul sorg wanneer kinders se biologiese ouers versuim om vir hulle 'n veilige en liefdevolle huis en omgewing te skep. Hierdie kinders kan ook ly aan of geaffekteer word deur Fetale Alkohol Spektrum Versteuring (FASV). Dit kan 'n groot skok wees wanneer versorgers uitvind dat die kind geaffekteer is daardeur, veral as hierdie versteuring misverstaan word. Professionele hulp is skaars, en intervensies en hulpbronne is nie vryelik beskikbaar nie. Versorgers is dikwels nie voorbereid op die finansiële, emosionele en fisiese eise wat nodig is om ten volle die kind se ontwikkeling te ondersteun nie. Dit kan dit lei tot verskillende emosionele reaksies met verskeie gevolge wat opsigself ook verskeie uitdagings vir die nie-biologiese versorgers veroorsaak.

Dit is van kritieke belang om die ervarings en uitdagings van ouerskap te verken in die bevordering en ontwikkeling van intervensiestrategieë ter ondersteuning van die behoeftes van die kinders met FASV en hul versorgers, veral vanuit 'n Suid-Afrikaanse perspektief. Daar word vereis van maatskaplike werkers om verantwoordelikheid te neem vir die aanspreek van FASV, aangesien hulle die professionele kapasiteit het om families wat geaffekteer is te help, en om hulle by te staan sodat 'n stabiele en koesterende huishouding ontwikkel en volgehou kan word. Een manier waarop dit bereik kan word, is deur die vestiging en fasilitering van ondersteuningsgroepe.

Die doel van hierdie studie was om 'n begrip te ontwikkel oor die ervarings van nie-biologiese versorgers van kinders met FASV se benutting van ondersteuningsgroepe. Die navorser het gebruik gemaak van 'n kombinasie van 'n verkennende en beskrywende navorsing. Deur die gebruik van beide 'n kwantitatiewe en kwalitatiewe benadering, is die navorser in staat gestel om 'n indiepte insig in die lewens van die versorgers te bekom, en ondersoek in te stel oor hul ervarings van die versteuring/gestremdheid deur ondersteuningsgroepe wat as intervensie aangewend is. Toestemming om die studie te doen is deur die Etiese Komitee vir Menslike Navorsing aan die Universiteit van Stellenbosch bekom.

Eerstens is die literatuurstudie voltooi waarin die navorser ondersoek ingestel het oor die implikasies van FASV op geaffekteerde kinders. Tweedens is daar bespreek hoe nie-biologiese versorgers geraak word deur die gevolge van hierdie versteuring/gestremdheid. Daarna is ondersteuningsgroepe as 'n metode van ondersteuning aan versorgers ondersoek, en klem is gelê op 'n wedersydse hulpbenadering en 'n opvoedkundige benadering as teoretiese grondslag.

Die empiriese studie is voltooi met 16 deelnemers deur middel van individuele, een-tot-een, semi-gestruktureerde onderhoude. 'n Onderhoudskedule, wat gebaseer is op die bevindinge van die literatuurstudie, is gebruik. Die kriteria vir deelname aan die studie en groep het ingesluit dat deelnemers ten minste vyf sessies van 'n ondersteuningsgroep moes bywoon en ook 'n pleegouer wees van 'n FASV kind.

Die resultate van hierdie studie het meestal die bevindinge uit die literatuurstudie bevestig en het getoon dat ondersteuningsgroepe 'n belangrike rol speel in ondersteuning aan nie-biologiese versorgers, wat dikwels onvoorbereid is op die werklike problematiek van die versorging van 'n kind met FASV.

Aanbevelings word gerig aan die maatskaplikewerk-professie in Suid-Afrika, ten einde ondersteuningsgroepe en ander metodes van dienslewering te bied, ter ondersteuning aan die versorgers van FASV kinders. Voorstelle vir verdere navorsing word ook gemaak sodat daar 'n ondersteuningsnetwerk opgebou kan word vir die versorgers van 'n FASV kind ten einde aan hulle unieke versorgingsbehoeftes te voorsien.



# TABLE OF CONTENTS

## CHAPTER 1

### INTRODUCTION

1.1	PRELIMINARY STUDY AND MOTIVATION FOR THE STUDY .....	1
1.2	PROBLEM STATEMENT AND FOCUS .....	5
1.3	AIMS OF RESEARCH PROGRAMME .....	6
1.4	CLARIFICATION OF KEY CONCEPTS .....	7
1.4.1	Fetal Alcohol Spectrum Disorder (FASD) .....	7
1.4.2	Non-biological caregiver .....	7
1.4.3	Child .....	8
1.4.4	Social group work .....	8
1.4.5	Support groups .....	8
1.4.6	Mutual aid group approach .....	9
1.4.7	Educational group approach .....	9
1.5	RESEARCH METHODOLOGY .....	9
1.5.1	Research approach .....	9
1.5.2	Research design .....	10
1.5.3	Research method .....	10
1.5.3.1	Literature study .....	10
1.5.3.2	Population and sampling .....	11
1.5.3.3	Method of data collection .....	12
1.5.3.4	Method of data analysis .....	12
1.5.3.5	Data confirmation .....	13
1.5.3.6	Ethical considerations .....	13
1.5.3.7	Limitations of study .....	14
1.6	PRESENTATION .....	14

## CHAPTER 2

### THE CONSEQUENCES OF FASD ON THE CHILD AND THE IMPLICATIONS FOR THE NON-BIOLOGICAL CAREGIVER

2.1	INTRODUCTION .....	15
2.2	PREVALENCE OF FASD IN SOUTH AFRICA .....	15
2.3	DIAGNOSING FASD .....	17
2.3.1	The difficulty to diagnose .....	18
2.3.2	The South African context of FASD .....	18
2.4	IMPLICATIONS FOR THE CHILD WITH FASD .....	20
2.4.1	Primary disabilities caused by FASD .....	21
2.4.1.1	Physical characteristics .....	21
2.4.1.2	Mental functioning .....	25
2.4.1.3	Behavioural challenges .....	26
2.4.1.4	Learning difficulties .....	28
2.4.2	Secondary disabilities caused by FASD .....	28
2.4.2.1	Mental health issues .....	29
2.4.2.2	Disrupted school experience .....	29
2.4.2.3	Trouble with the law .....	30
2.4.2.4	Inappropriate sexual behaviour .....	31
2.4.2.5	Drug and alcohol abuse .....	31
2.4.2.6	Difficulty with independent living .....	31
2.4.2.7	Difficulty with employment .....	31
2.4.3	Protective Factors against secondary disabilities .....	32
2.5	THE FASD CHILD PLACED IN ALTERNATIVE CARE .....	32
2.6	CHALLENGES FACED AS A RESULT OF FASD CHILD ENTERING THE HOUSEHOLD .....	36
2.6.1	Education for a child with FASD .....	36
2.6.2	Keeping the FASD child involved in society and public .....	37
2.6.3	Adapting the household for the FASD child .....	38
2.6.4	Dealing with new and continuous behavioural problems .....	38

2.7	IMPLICATIONS FOR THE CAREGIVER .....	39
2.7.1	Emotional conflict .....	40
2.7.2	Continuous setbacks .....	40
2.7.3	High levels of stress .....	41
2.7.4	Exhaustion .....	42
2.7.5	Caring for self .....	42
2.7.6	Needing respite care .....	43
2.7.7	A battle for support .....	44
2.7.8	Forever parenting .....	45
2.7.9	Taken for granted and feeling unappreciated .....	45
2.7.10	Keeping and making plans .....	46
2.7.11	Experiencing loss and grief .....	46
2.7.12	Experiencing fear and hopelessness .....	47
2.7.13	Feeling judged by others .....	47
2.8	IMPLICATIONS ON OTHER MEMBERS OF THE FAMILY .....	48
2.9	CONCLUSION .....	48

## **CHAPTER 3**

### **THE UTILISATION OF SUPPORT GROUPS IN ORDER TO CARE FOR THE CHILD WITH FASD**

3.1	INTRODUCTION .....	50
3.2	THE NEED FOR SUPPORT .....	51
3.3	TYPES OF SUPPORT AVAILABLE TO CAREGIVERS OF FASD CHILDREN .....	52
3.4	GAINING SUPPORT .....	54
3.5	THE SOCIAL WORK RESPONSE .....	55
3.6	THE GROUP WORK METHOD .....	56
3.7	TYPES OF GROUPS .....	57
3.8	THE SUPPORT GROUP .....	58
3.8.1	Emotional support .....	59

3.8.1.1	Absolute respect and non-judgmentalism .....	59
3.8.1.2	Reciprocal relations to other caregivers .....	59
3.8.1.3	Normalization of circumstances .....	60
3.8.1.4	Enabling of significant emotional progressions .....	60
3.8.2	Practical support .....	60
3.8.2.1	Enabling for a change in thought-patterns regarding FASD .....	60
3.8.2.2	An opportunity for respite/rest .....	61
3.8.2.3	Linking to resources .....	61
3.8.2.4	Advocacy within caregiver support groups .....	61
3.8.2.5	Innovation and training .....	61
3.8.2.6	Practical tools .....	61
3.9	APPROACHES TO SUPPORT GROUPS .....	62
3.9.1	The mutual aid approach .....	62
3.9.1.1	Primary functions of mutual aid groups .....	63
3.9.1.2	The nine dynamics/Processes of mutual aid .....	64
	(a) Sharing data .....	64
	(b) The dialectic process .....	65
	(c) Discussing taboos .....	65
	(d) All in the same boat .....	66
	(e) Mutual support .....	67
	(f) Mutual demand .....	68
	(g) Individual problem solving .....	68
	(h) Rehearsal .....	68
	(i) Strength in numbers .....	69
3.9.2	The educational approach .....	69
3.10	POSITIVE AND NEGATIVE ASPECTS OF SUPPORT GROUPS .....	73
3.10.1	Positive aspects .....	73
3.10.1.1	Expand understanding on FASD .....	73
3.10.1.2	Help caregiver to help the child .....	74
3.10.1.3	Acquiring and employing new strategies .....	74
3.10.1.4	Sharing experiences .....	74
3.10.1.5	Finding mutuality .....	74

3.10.1.6 Using humour .....	74
3.10.1.7 Inspiring hope .....	75
3.10.1.8 Mentorship .....	75
3.10.2 Negative aspects .....	75
3.10.2.1 Anticipating future challenges .....	75
3.10.2.2 Disappointment in group process .....	75
3.10.2.3 Poor operational functioning .....	76
3.10.2.4 One-size-fits all mentality .....	76
3.10.2.5 Friction within the group .....	76
3.10.2.6 Jealousy over other members .....	76
3.11 CONCLUSION .....	76

## CHAPTER 4

### FINDINGS FROM THE EMPIRICAL STUDY REGARDING THE UTILISATION OF SUPPORT GROUPS FOR NON-BIOLOGICAL CAREGIVERS OF CHILDREN WITH FASD

4.1 INTRODUCTION .....	78
4.2 DELIMITATION OF THE INVESTIGATION .....	79
4.3 GATHERING AND ANALYSING DATA .....	79
4.4 RESULTS OF INVESTIGATION .....	85
4.4.1 Identifying details (Theme 1) .....	85
4.4.1.1 Residential area of non-biological caregivers (Sub-theme 1.1) .....	85
4.4.1.2 The time period in which the non-biological caregivers have cared for children affected by FASD (Sub-theme 1.2) .....	85
4.4.1.3 Caregiving relationship to children (Sub-theme 1.3) .....	86
4.4.2 Implications of FASD on children (Theme 2) .....	88
4.4.2.1 Knowledge of FASD before affected children enter placements (Sub-theme 2.1) .....	88

4.4.2.2	Reactions to when finding out the children are affected by FASD (Sub-theme 2.2) .....	88
4.4.3	The extent to which non-biological caregivers are affected by the consequences of FASD (Theme 3) .....	90
4.4.3.1	Areas of challenge (Sub-theme 3.1) .....	90
4.4.3.2	Implications due to FASD ((Sub-theme 3.2) .....	93
4.4.3.3	Being able to access services to assist caregivers in caring for the FASD children (Sub-theme 3.3) .....	97
4.4.3.4	Social worker's understanding of FASD and the ability to render services to support the non-biological caregivers (Sub-theme 3.4) .....	99
4.4.3.5	Other children and family members in the household being affected (Sub-theme 3.5) .....	103
4.4.3.6	The understanding of FASD by extended family and friends and their ability to support the non-biological caregivers (Sub-theme 3.6) .....	104
4.4.4	The utilisation and experiences of a support group (Theme 4) .....	105
4.4.4.1	The need for support in caring for children affected by FASD (Sub-theme 4.1) .....	105
4.4.4.2	Support groups playing a vital role in supporting non-biological caregivers of FASD children (Sub-theme 4.2) .....	105
4.4.4.3	Amount of sessions attended (Sub-theme 4.3) .....	108
4.4.4.4	Ways in which support groups helped non-biological caregivers to cope better (Sub-theme 4.4) .....	108
4.4.4.5	Meeting the group member's expectations about the group sessions (Sub-theme 4.5) .....	110
4.4.4.6	Emotional support in the support group context (Sub-theme 4.6) .....	110
4.4.4.7	Practical support in the support group context (Sub-theme 4.7) .....	115
4.4.4.8	Approaches in support groups (Sub-theme 4.8) .....	120
4.4.4.9	Positive aspects within a support group (Sub-theme 4.9) .....	129
4.4.4.10	Negative aspects within a support group (Sub-theme 4.10) .....	133
4.4.4.11	Recommendations or changes for support groups suggested by non- biological caregivers (Sub-theme 4.11) .....	135

4.5	CONCLUSION .....	137
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## CHAPTER 5

### CONCLUSIONS AND RECOMMENDATIONS

5.1	INTRODUCTION .....	138
5.2	CONCLUSIONS AND RECOMMENDATIONS .....	138
5.2.1	Identifying details .....	138
5.2.2	Implications of FASD .....	139
5.2.3	The extent to which non-biological caregivers are affected by the consequences of FASD .....	140
5.2.3.1	Areas of challenge .....	140
5.2.3.2	Implications due to FASD .....	142
5.2.3.3	Being able to access services to assist non-biological caregivers in caring for the FASD children .....	145
5.2.3.4	Social worker's understanding of FASD and the ability to render services to support non-biological caregivers .....	147
5.2.3.5	Other children and family members in the household being affected .....	148
5.2.3.6	The understanding of FASD by extended family members and friends and their ability to support non-biological caregivers .....	149
5.2.4	The utilisation and experiences of a support group .....	150
5.2.4.1	The need for support in caring for children affected by FASD .....	150
5.2.4.2	Support groups playing a vital role in supporting non-biological caregiver .....	150
5.2.4.3	Ways in which support groups help non-biological caregivers cope better .....	151
5.2.4.4	Meeting the group member's expectations about the group sessions .....	152
5.2.4.5	Emotional support in the support group context .....	152
5.2.4.6	Practical support in the support group context .....	154
5.2.4.7	Approaches in support groups .....	156

5.2.4.8	Positive aspects within a support group .....	159
5.2.4.9	Negative aspects within a support group .....	161
5.2.4.10	Recommendations or changes for support groups suggested by non- biological caregivers .....	162
5.3	RECOMMENDATIONS FOR FUTURE RESEARCH .....	163
5.4	FINAL CONCLUSION .....	164
	BIBLIOGRAPHY .....	165

## **ANNEXURES**

ANNEXURE A:	CONSENT FORM- ENGLISH .....	177
ANNEXURE B:	CONSENT FORM- AFRIKAANS .....	180
ANNEXURE C:	QUESTIONNAIRE-ENGLISH .....	183
ANNEXURE D:	QUESTIONNAIRE- AFRIKAANS .....	190
ANNEXURE E:	PERMISSION LETTER FROM HOME OF HOPE .....	197



## LIST OF FIGURES

Figure 2.1	Facial dysmorphology associated with FASD .....	22
Figure 2.2	Development of foetus and genetic abnormalities .....	23
Figure 2.3	Picture of normal brain compared to FAS brain .....	24
Figure 2.4	Side scan of a normal brain (left) compared to an alcohol exposed brain (right) .....	25
Figure 4.1	Presentation of caregiving role to children .....	87
Figure 4.2	Amount of support group sessions attended at time of interview .....	108
Figure 4.3	Emotional support in the support group context .....	111
Figure 4.4	Practical support in the support group context .....	115
Figure 4.5	Positive aspects experienced in the support group context .....	130
Figure 4.6	Negative aspects experienced in the support group context .....	133

## LIST OF TABLES

Table 4.1	Schematic representation of empirical Study .....	81
Table 4.2	Time period of non-biological caregiving role to FASD children .....	86
Table 4.3	Possible reactions to finding out the children are affected by FASD .....	89
Table 4.4	Challenges faced by non-biological caregivers .....	90
Table 4.5	Implications experienced by non-biological caregivers as a result of caring for FASD children.....	93

## CHAPTER 1

### INTRODUCTION TO STUDY

#### 1.1 PRELIMINARY STUDY AND MOTIVATION FOR THE STUDY

An effort to prevent alcohol exposed pregnancies have increased over the years, but despite these efforts children are still being born with Fetal Alcohol Spectrum Disorders and it is recognised today as the highest form of developmental disabilities in the world (Bertrand, 2009). Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term used to explain the range of effects that occur as a result of a pregnant mother's alcohol use. The baby born may show permanent disabilities in areas of physical growth, mental capacity, behaviour and learning abilities as development takes place over time (Warren, Hewitt & Thomas, 2011). FASD is not a diagnostic criteria in itself, but includes the following diagnoses: Fetal Alcohol Syndrome (FAS), the severest form among the FASDs; Partial Fetal Alcohol Syndrome (PFAS) and Alcohol-Related Neurological Disorder (ARND), which is characterised by a range of neurological impairments, but no apparent growth deficiency or facial characteristics; and Alcohol-Related Birth Defects (ARBD), which refers to abnormalities in other organs, skeletal abnormalities and vision and hearing problems (Ipsiroglu, McKellin, Carey & Loock, 2013).

Disabilities associated to FASD will continue across the life span and there is no cure. This reality will possibly pose difficulty due to heavy financial and emotional consequences on the individual and affected family (Warren *et al.*, 2011).

South Africa has a normative culture of drinking which often filters into pregnancy (Jansen Van Vuuren & Learmonth, 2013). The Integrated Service Delivery Model for social work in South Africa aim at rendering services at various levels on a continuum with prevention and early intervention being first (Department of Social Development, 2006). Despite awareness programmes and prevention efforts in South Africa done by various organisations such as FARR, FASDA and FASfacts that specialise in addressing alcohol related issues during pregnancy, many women are continuing their drinking patterns (Marais, Jordaan, Olivier & Viljoen, 2013; FASfacts, 2013; FARR, 2013; FASDA, 2013). Considering this statement, it is to no surprise that FAS is becoming a growing concern in South Africa.

Prevalence rates for this disability are the highest in the Western Cape and is simultaneously claimed to be the highest in the world (Jansen Van Vuuren & Learmonth, 2013). Recent statistics show that at least 6 million people are affected by FASD in South Africa (FARR, 2013). These increasing alcohol use patterns are a result of adverse factors caused by heritage, unemployment, poverty and low-paid menial jobs, depression, low self-esteem and efficacy, increased access to legal and illegal alcohol and lack of recreational activities, poor education, familial pressure and cultural misconceptions (Jansen Van Vuuren & Learmonth, 2013).

A study done by May, Gossage, Brooke, Snell, Marais, Hendricks, Croxford and Viljoen (2005) reported that up to 50% of women in the Western Cape consume alcohol during their pregnancies. Furthermore, a recent study completed in a community in Western Cape (Watt, Eaton, Choi, Velloza, Kalichman, Skinner & Sikkema, 2014) showed that women were involved in heavy drinking patterns during their pregnancy, with the majority consuming as much during pregnancy as they had preceding pregnancy. Despite overall knowledge about the damaging effect that alcohol intake during pregnancy could have on baby, a large majority of this sample continued to drink hazardously right through the pregnancy.

Regardless of these staggering heights of alcohol usage during pregnancy and increasing public concern, little is known about the utilisation and costs of health care services or intervention that is available for the affected individuals and families (Credé, Sinanovic, Adnams & London, 2011). Together with this, there is general ignorance about the nature and consequences of FASD and the lack of day-to-day support that is available to those in needs. This is resulting in serious implications for the health care sector as the need for various medical interventions as a result of this disability will increase (Rutman & Van Bibber, 2010). Implications for the justice sector will also be prevalent as individuals with FASD often have low intelligence, show behavioural problems and have poor social judgement and do not understand consequences of their actions which place them in a vulnerable position of being forced into the engagement of criminal activity (Marais *et al.*, 2013).

Effects of FASD may vary significantly in severity between individuals but studies show that over time the effects can be improved or intensified by family contexts (Brown & Bednar, 2004). Children with FASD are often placed in foster care arrangements from a very young age due to unacceptable

environmental living conditions which results in the need for statutory services (ISDM, 2006) for the affected child and new non-biological caregivers. Learning of a child's disability can be a big shock to non-biological caregivers especially if it is misunderstood, available professional help is scarce and intervention resources are not readily available. This lack of support will result in the family systems feeling isolated, alone and unable to manage (Whitehurst, 2011). Research done by Williams, Dubovsky and Merrit (2011) confirm that non-biological caregivers are very often tremendously ill-prepared and uneducated about FASD and they do not understand the consequences of this disability. These non-biological caregivers are often not prepared for the financial, emotional and physical investment that is required to fully support the children and their development. Those factors often cause frustration and anger in the non-biological caregivers' life and can result in an increased risk for child abuse (Williams *et al.*, 2011). Adding to the major adaptations that are required is the exposure to stigmatization and social stereotyping of their children by family, friends and society (Banks, 2003). A study conducted by Rutman and Bibber (2010) revealed that non-biological caregivers struggle to navigate their own personal lives and that of their children. Another study conducted by Whitehurst (2011) revealed that a great deal of emotional conflict is experienced, that there is a lack of professional knowledge of FASD and that there is a major lack of support for them and their families.

Non-biological caregivers often take children into their care when these children's own biological caregivers of families have failed to do so and no alternative place of safety is available. Non-biological carers provide love, support and care for these affected children. It is for this reason that necessary steps should be taken to ensure that they are supported and that services are available to them as carers of children. Porty (2009) states that non-biological caregivers are an absolute valuable resource for children with FASD and research have shown that a supportive, conscientious and nurturing home may be the best way of improving and easing a child's diagnosis (Toutain & Lejeune, 2008). It is however important to note that very few research studies have been done to examine the contribution of effective intervention strategies that are available for the non-biological caregivers for the purpose of preventing caregiver exhaustion and ensuring that the child's needs are provided for (Brown, Bednar & Sigvaldason, 2007).

A strong international statement was made by Pelech, Bardy and Daoust (2013) about the existing general belief in child welfare practice that children with alcoholic caregivers are better off in alternative care. There is not much that can be said to challenge this discourse if caregivers refuse to change their behaviour and ensure the emotional and physical well-being of their affected children. As a result of this, the need for intervention studies surrounding support structures for non-biological caregivers is vital in the field of child welfare practice. From the above observation, it is critical to recognise parenting experiences and challenges as a means of developing and promoting intervention strategies and support that will respond to the needs of the children with FASD and their non-biological caregivers (Brown & Bednar, 2004), especially from a South African perspective.

Kortla and Martin (2009) shared a need for social workers to take on responsibility for addressing FASD as they have the professional capacity to help families living with FASD to develop and maintain stable and nurturing households. One way in which this can be achieved is through support groups (Kortla & Martin, 2009). Within these groups an opportunity for strategy and success sharing is possible which will improve efficacy and strengthen social support systems. The social work profession is in a very unique position to initiate and facilitate such opportunities (Kortla & Martin, 2009). Cases in which such support groups have been established and utilised have been recorded and non-biological caregivers have benefitted from them (Bertrand, 2009). General feedback included reduced isolation, non-judgemental environments, peer support, normalisation of their own personal issues and stress, mentorship, education, practical help, overall support and a general investment in seeing their respective families succeed (Porty, 2009).

The researcher has accumulated literature (Porty, 2009) to confirm the contribution of support groups as part of the continuum of care for families with disabilities but have noticed that all are based on an international scope. Recent studies completed in South Africa around the topic of FASD have confirmed the need for education through parent training programmes for non-biological caregivers (Cloete, 2013). Chirwa (2012) completed a study on the experiences of mothers caring for their children with physical or mental disabilities in low-income communities in South Africa and recommended that non-biological caregivers should be provided with social support through informal support groups. No studies could be found specifically related to the experiences of non-biological

caregivers of their utilisation of this type of group and it is for this reason that a more local understanding be developed and that an exploration on this topic is undertaken from a South African perspective.

According to Butler and Wintram (1991) group work serve significance in the following ways: as a source of immediate support where the knowledge that the meeting will take place regularly is a safety net in itself; serving to be a place where shared experiences are valued and recognised; providing a way for isolation and loneliness to be broken; a source where different perspectives can be shared on how to deal with personal problems and lastly a place where power can be experienced over personal situations with the capacity to change them. Therefore, this study will be based on group work theory with specific reference to the mutual aid approach and the educational approach. Garvin, Gutiérrez & Galinsky (2004) explains mutual aid as alliance of individuals that need each other and the professional worker. Within this context, helping systems are created to work on common life issues, interests and tasks. The mutual aid approach is distinguished from other groups by using supportive intervention strategies through the primary goals of fostering mutual aid, helping members cope with stressful life events and to enable members to enhance their coping abilities for current situations as well as future situations that might be stressful (Toseland & Rivas, 2005). An educational approach aims to develop long-term bodies of knowledge and produce problem solving skills that will assist group members to solve personal problems, both in the present and in the future (Hatfield, 1994). The described theoretical underpinning will allow for the researcher to investigate the utilisation of support groups as a group work intervention method in helping non-biological caregivers cope with the challenges of providing care for their affected children.

## **1.2 PROBLEM STATEMENT AND FOCUS**

Research (Pelech *et al.*, 2013; Porty, 2009 & Whitehurst, 2011) clearly states that children with FASD often struggle to adapt to caregiver arrangements due to a lack of support and knowledge of this disability. Therefore an emphasis should be placed on exploring factors best suited in supporting involved families and non-biological caregivers. Olson, Rosalind, Gelo and Beck (2009) also found that support for the family and non-biological caregivers is a pivotal factor in helping the child with FASD succeed daily. If this is successfully achieved a more stable and nurturing home environment will be

created (Porty, 2009). In general, relatively few studies across the world have been done on the experiences of specifically non-biological caregivers of children with FASD (Brown *et al.*, 2007). Moreover, the majority of the studies about non-biological caregivers' experiences of support groups that have been done are based on other countries (Brown & Bednar, 2008; Brown *et al.*, 2007; Porty, 2009; Ruthman & Bibber, 2010; Whitehurst, 2011) and a gap in research and insight into this topic exist from a South African context.

Olson *et al.* (2009) highlighted that data on self-reported experiences and parenting behaviour should aim at furthering research on possible intervention that will increase self-efficacy, increase available resources and provide support that takes a different approach to education alone. Whitehurst (2011) concluded that by listening to the voices of such non-biological caregivers, support will match the expressed needs and will contribute in benefitting not only them, but also the children with FASD. Based on this problem statement, **the following question can be formulated:** *What are the experiences of non-biological caregivers of FASD children and are they able to utilise support groups?*

### **1.3 AIMS OF RESEARCH PROGRAMME**

The goal of the study is to gain an understanding on the experiences of non-biological caregivers of children with FASD and of the utilisation of support groups to help them cope.

In order to achieve this, the following objectives are outlined;

- To explain the implication of FASD on children and to specifically highlight the extent to which non-biological caregivers are affected by the consequences of this disability.
- To describe the utilisation of support groups, with the emphasis on a mutual-aid and educational approach as theoretical underpinning of support groups for non-biological caregivers to improve their ability to care for children diagnosed with FASD.
- To empirically investigate non-biological caregivers experiences' of FASD and the utilisation of support groups.
- To make conclusions and recommendations on the utilisation of support groups by non-biological caregivers of children with FASD based on empirical findings.

## 1.4 CLARIFICATION OF KEY CONCEPTS

For the aim of the research the following concepts will be clarified:

### 1.4.1 Fetal Alcohol Spectrum Disorder (FASD)

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term used to describe the range of effects that occur as a result of prenatal alcohol use. The individual may show permanent disabilities in areas of physical growth, mental capacity, behaviour and learning abilities (Warren *et al.*, 2011). FASD is not a diagnostic criteria in itself but encompass the following diagnoses: Fetal Alcohol Syndrome, the severest form among the FASD's; Partial Fetal Alcohol Syndrome (PFAS) and Alcohol-Related Neurological Disorder (ARND), characterised by a range of neurological impairments, but no evident growth deficiency or facial characteristics; and Alcohol-Related Birth Defects (ARBD), which refer to defects in other organs, skeletal abnormalities and vision and hearing problems (Ipsiroglu *et al.*, 2013).

### 1.4.2 Non-biological caregiver

An individual who is not the biological parent of the children who provide for the emotional, physical, and social needs of others who are often dependent and unable to provide for their own needs (Barker, 1995). For the study this will include:

- *Foster care*: A child-centred service in the form of statutory substitute care that is provided for children who cannot be cared for by their biological parent/s in short, medium or long term (Whitepaper, 1997).
- *Cluster foster care*: Defined as foster care but where a total of not more than six foster children are placed in one household (Whitepaper, 1997).
- *Adoption*: A child protection and preventative service, and an effective means of permanency planning for children whose families of origin are unable to care for them (Whitepaper, 1997).
- *Youth Care Centre*: A facility for the provision of residential care to more than six children outside the child's family environment in accordance with a residential care programme suited for the children in the facility (Children's Act, 2005).



- *Respite care*: Respite care provides a caregiver temporary relief from the responsibilities of caring for individuals with chronic or mental disabilities. The primary purpose of respite care is to relieve caregiver stress, thereby enabling them to continue caring for the individuals with a disability (Encyclopaedia of Mental Disorders, 2014).
- *Youth care worker*: An individual who works in the life space of children and adolescents with both normal and special development needs to promote and facilitate optimal development through the intentional use of everyday life events and programs that assist in their capacity to function successfully within different settings (AIDSTaR-Two Project, 2013).

### **1.4.3 Child**

According to Barker (1995) a child is an individual who is usually in a life stage of rapid physical growth. This stage occurs after infancy and lasts until adulthood. According to the Children's Act no. 38 of 2005 a child is a person under the age of 18 years (Children's Act, 2005).

### **1.4.4 Social group work**

According to Barker (1987), a primary author on social group work, this method of intervention is executed with a small amount of people who share a common need or interest. They assemble regularly and engage in activities intended to attain their shared goals. These goals can include: treatment of emotional concerns, information sharing, and development of social skills or redirecting antisocial behaviour to more productive outlets. Toseland and Rivas (2005) explain group work as a goal-directed activity aimed at completing tasks and meeting socio-emotional needs of the group members. This activity is directed both at the individual group members as well as the group as a whole within a system of service delivery.

### **1.4.5 Support groups**

A support group may be defined as a planned and continuous series of meetings between individuals who share a common problem. Within these groups encouragement, advice, information and emotional sustenance are provided as a means of providing support. The group may be led by a professional or consist only of the members themselves. The degree of structure varies significantly (Barker, 1995). This type of group work uses supportive intervention strategies as primary goal in

order to foster mutual aid, to help members cope with stressful events and to increase the coping abilities of group members so that they are able to adapt and cope with possible future event that may be stressful (Toseland & Rivas, 2005).

#### **1.4.6 Mutual aid group approach**

A mutual aid approach refers to mutual aid where individuals endeavour to form an alliance in order to work on a common problem. A helping system is created where the individuals need each other and the worker in order to create helping relationships, which is a vital ingredient in the group process. Mutual bonds are formed, collective support is experienced, mastery over personal environments is achieved and feelings of isolation are overcome (Garvin *et al.*, 2004).

#### **1.4.7 Educational group approach**

An educational approach mainly functions to develop long-term bodies of knowledge and produce problem solving skills that will assist group members to solve personal problems, both in the present and in the future. The focus is on both the broad application of what is learned and the maintenance thereof over time (Hatfield, 1994).

### **1.5 RESEARCH METHODOLOGY**

#### **1.5.1 Research approach**

In order to complete this study, both *quantitative* and *qualitative* research is undertaken. This is done in order to achieve a more complete understanding of the research problem (De Vos, Strydom, Fouché & Delport, 2011). *Quantitative* and *qualitative* research differs in some ways, but there are aspects which merge them together (Salkind, 2012). The *quantitative* approach takes on a more scientific stance with the main aim being the measurement of the social world in an objective manner and also testing hypothesis in such a way. From a *qualitative* perspective, the researcher is concerned with understanding a phenomena from the participants' point of view with the aim of understanding a complex situation in depth (De Vos *et al.*, 2011). This approach also allows for the researcher to gain descriptive answers as well as being able to work with more analytical questions (Greener, 2011). By using both a quantitative and qualitative approach, the researcher can use the two approaches in a complimentary manner as a means of gaining an in depth insight into the lives of the non-biological

caregivers and how they experience this disability and support groups that are utilised as a means of helping them cope.

### **1.5.2 Research design**

A research design is the plan that outlines how observations will be made and how the research project will be carried out (De Vos *et al.*, 2011). The researcher is making use of a combination of an exploratory and descriptive research design. An *exploratory* design allowed for the gaining of insight into a certain phenomenon by becoming accustomed to the basic facts and to create a broad picture of the conditions there of (De Vos *et al.*, 2011). The researcher found this applicable as it allowed for insight into the consequences of FASD as well as seeking an understanding of how the non-biological caregivers experience this phenomenon. A *descriptive* study design allowed for an intensive examination of a phenomenon and their deeper meanings allowing for a thicker description (Rubin and Babbie, 2001). This design is used to closely examine the utilisation of support groups for non-biological caregivers of children diagnosed with FASD in South Africa.

### **1.5.3 Research method**

Within the following section, an outlay of the process of investigation will be given.

#### **1.5.3.1 Literature study**

According to De Vos *et al.* (2011) an in-depth literature study is pivotal in creating a comprehensive understanding of the nature and meaning of the proposed problem that is being researched. It ensures that a foundation of existing knowledge is formed which will place the researcher in a position to make well informed decisions with regards to the specific problem that is explored. By conducting a thorough literature study, the researcher became aware of possible gaps which in return provided credibility to the proposed study. The literature study focussed on gaining insight from various sources that provided information regarding the support that is provided to non-biological caregivers of FASD children in South Africa and what their experiences are thereof.

### **1.5.3.2 Population and sampling**

The *Universe* of a research study refers to all the potential subjects who possess the attributes in which the researcher is interested (De Vos *et al.*, 2011). For this study it constituted all parties involved in caring for children with FASD.

The *Population* of a research study is the group of candidates that remain when certain boundaries are put into place and certain characteristics are considered, thus it is the individuals who are of importance to the researcher (Salkind, 2012). For the purpose of this study, the researcher specifically refers to non-biological caregivers that are involved in caring for children with FASD.

The *sample* of the study will be chosen as a subset from the population that will be included in the study (De Vos *et al.*, 2011). A sample is also chosen as a small representative body of the total population as it will be too costly and time consuming to study the population in its entirety. The data that was collected from this sample was then assumed for the rest of the population.

The research study made specific use of *purposive sampling* for the fact that it will allow for a sample to be selected from the population on the basis of representing the most characteristics and attributes sought after for the study (De Vos *et al.*, 2011). A *non-probability sampling* method is used when the researcher does not have information regarding the size and particulars of the population (De Vos *et al.*, 2011). Within this method, the individuals of the population do not all stand an equal chance of being selected for the sample (Jackson, 2009). The *sample* of this study consists of 16 non-biological caregivers of children with FASD who have been exposed to a support programme in the Western Cape specifically related to this disability. This enabled the researcher to understand their experiences surrounding the utilisation of support that is provided for them as non-biological caregivers in order to provide the FASD children with a caring and stable environment in which to grow.

The *criteria for inclusion* included the following: the participants of the study could be of any race or culture, has to be a non-biological caregiver of a child between the age of 0-18 years of age with FASD, they may not be the biological mother or father of the child, but could be related to the child through foster care, cluster foster homes, adoption and youth care facilities. This study does not aim

to look only at foster care primarily but at all possible alternative care options other than biological parents. These potential non-biological caregivers also had to attend at least 5 sessions of a support group offered as help with the challenges of caring for the effected children. A reflection is offered in chapter four on the research methodology and specifically on the sampling.

### **1.5.3.3 Method of data collection**

*Semi-structured, one-on-one interviews* (annexure C/ D) are organised around an area of particular interest which still provides space for flexibility if it is needed (De Vos *et al.*, 2011). An interview schedule was created and is utilised during this research study. This method allowed for the participants to share their personal experiences and beliefs in a rich and detailed manner which closely links to the aim of qualitative research (De Vos *et al.*, 2011). It is further explained that *semi-structured interviews* are best suited for studies where the aim is to understand complexities or issues that are controversial and personal. Predetermined questions were set up, but the interviews were guided rather than dictated by the schedule (De Vos *et al.*, 2011).

A *Pilot study* is used for two main reasons; to ensure the validity and content of the measuring instrument and secondly, to estimate the time it takes to complete the proposed interview (De Vos *et al.*, 2011). For this research, a pilot test was done with 2 participants who qualified for inclusion in order to ensure that no questions were ambiguous or limiting to the study. Necessary amendments were made.

### **1.5.3.4 Method of data analysis**

According to De Vos *et al.* (2011) *data analysis* is the process where big quantities of raw information is reviewed and sifted through to identify important patterns in order to communicate what the research study reveals. There are several stages that were followed; firstly the researcher reduced fully transcribed information into themes, sub-themes and categories. Categories of quantitative and qualitative data were then displayed through graphs and tables. Thirdly, the quantitative data and qualitative data were then correlated. After this, new data was identified from the correlated data. Next the findings were compared to other sources and lastly, the findings were fully integrated and displayed after which conclusions were drawn and recommendations were made.

#### **1.5.3.5 Data confirmation**

Marshall and Rossman (1995) noted that all research projects need to be tested for credibility and trustworthiness. Lincoln and Guba (1985) identified four categories that assist in determining whether the finding of a research project is truthful.

*Credibility* is achieved when a clear and concise depiction of the subject of the study is provided. The researcher achieved this by giving clear identifying details of her participants. *Transferability* seeks to determine whether or not the presented study can be transferred from one case to the next, this was successfully achieved in this research study through referring to other studies in a similar field. *Dependability* is achieved when the research study findings can be replicated in another study; this was achieved by the compilation of a research document available to other researchers. *Conformability* is achieved when findings are not influenced by personal biases but on the collected data itself. This was achieved through the guidance and monitoring of the researcher's supervisor (De Vos, 2009).

#### **1.5.3.6 Ethical considerations**

According to De Vos *et al.* (2011) research studies need to be based on a foundation of trust, cooperation, clear expectations and acceptance between all parties involved. The fact that the study is also based on the experiences of human beings brings various challenges to the fore. The researcher ensured that no unnecessary risks were taken and nothing was done at the expense of the participants.

*Informed consent* (annexure A/ B) was obtained in order to ensure that the goal of the research study and all the relevant information and logistical aspects were understood by each participant as well as what the expectations were of them as participants (De Vos *et al.*, 2011). Each participant signed two copies of a consent form; one which is kept securely and the other which was handed to the participant.

The researcher also re-iterated the fact that complete *confidentiality and anonymity* will be kept at all times and that only the most necessary personal information will be gathered for the study. Any personal data that was gathered will be kept safe. Participants were informed that they have the full

right to refuse to answer questions that they feel uncomfortable with and that they may withdraw at any time during the interview.

*Ethical clearance* (annexure E) was obtained by a non-profit organisation which offered support groups for caregivers of FASD children as well as the *Departmental Ethics Screening at the University of Stellenbosch*.

#### **1.5.3.7 Limitations of study**

A limitation to this study is the fact the participants were all recruited from support groups offered by one organisation. This could be limiting on the type of group work that is utilised in other groups. Another limitation could be that all of the participants were from the same geographical area and have received some form of support for their disabled child which may not fully represent the challenges that the majority of non-biological caregivers with FASD children in South Africa struggle with. However, participants of this study came from various cultural backgrounds which allowed for the gathering of rich information. The aim of this study is not necessarily to generalise but to understand the experiences of non-biological caregivers of FASD children.

### **1.6 PRESENTATION**

The study consists of several chapters as follows below;

Chapter 1 serves as an introduction and overview of the study.

Chapter 2 serves the purpose of giving the reader a clear understanding of the consequences of FASD on the child and the implications for the non-biological caregiver.

Chapter 3 examines how support groups are utilised in order to help non-biological caregivers care for their children with FASD. This will be done by referring to the components of support groups and the mutual aid- and educational approach.

Chapter 4 presents the data that is collected during the empirical study.

Chapter 5 includes the conclusions and recommendations based on chapter 4.

## **CHAPTER 2**

### **THE CONSEQUENCES OF FASD ON THE CHILD AND THE IMPLICATIONS FOR THE NON-BIOLOGICAL CAREGIVER**

#### **2.1 INTRODUCTION**

When a child is born with an irreversible disability caused by prenatal alcohol abuse a vast number of factors need to be recognized and contemplated not only by caregivers, but also by all role players and support networks surrounding them. Within this chapter, the researcher aims to give the reader an overview of the challenges South Africa is facing in diagnosing and providing services to FASD children and their families. The implications of the disability on the child will be discussed by looking at how they are affected. Together with this discussion, the extent to which the non-biological caregivers are affected by the ramifications of this disability will be discussed based on national and international literature.

#### **2.2 PREVALENCE OF FASD IN SOUTH AFRICA**

South Africa is known for having the highest FASD prevalence rate in the world and recent statistics show that at least 6 million people are affected by FASD in South Africa (FARR, 2013). Regardless of this no integrated national strategy, policy or on-going surveillance is in place to deal effectively with this ever growing problem (Marias, Jordaan, Olivier & Viljoen, 2013). There are, however, efforts being made by various South African partners in the field of FASD (Marais et al., 2013). Research conducted by FARR showed that primary health care staff, educational staff and social workers did not possess the necessary skills and/or knowledge to deal with affected children. Governmental departments and social organizations have also been slow to respond to the FASD phenomenon (Viljoen, 2009). FASD incidences seem to occur less frequently compared to other health problems such as TB, Malaria, HIV/ Aids and Malnutrition which currently dominate statistically in South Africa. This means FASD receives less attention from both media and public health communities (Davies, Chetty, Molteno, Olivier & Viljoen, 2008). It is not considered that the costs associated with this



disorder far outweigh the prevalence rates and that the consequences of this disorder are enormous (Rendall-Mkosi, London, Adnams, Morojele, McLoughlin & Goldstone, 2008).

South Africa does not have a national observation system for FAS; neither does it have local observation networks, even in high risk areas. The creation of these observation networks is complicated by a number of factors including; screening and diagnostic problems, specialist attainability and ethical considerations. The inadequate information that is available further complicates if not making it impossible, to derive valid and specific measurements of national FAS and FASD prevalence (Rendall-Mkosi *et al.*, 2008).

A study was done by McLoughlin, Rendall-Mkosi, Morojele, London, Adnams and Goldstone (2008) and it was found that only two policy documents contained the term FAS and none contained FASD. These two documents are The National Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities (Department of Health, 2001) and the National Drug Master Plan (Department of Social Development, 2007). A National FAS Task Team that has been created was found to be limited in their planning, vision and operation with very little multi-sectoral relations and being mainly represented by the Department of Health (McLoughlin *et al.*, 2008). Representatives of this team were also not senior enough to make decisions that could change the perceived notions and resource distribution that would make a difference (Rendall-Mkosi *et al.*, 2008). This is concerning since FASD has an impact on all facets of society. There are two provinces that have active task teams, but specialist teams that can diagnose children with FASD are extremely scarce (McLoughlin *et al.*, 2008).

Numbers of affected individuals in Gauteng showed that FASD is not a problem exclusive to wine making and/or rural areas in South Africa. There is no national prevalence data on FAS or the continuum of FASD. Given the high rates of FAS in high risk communities, it is likely that the rates for the milder conditions on the FASD continuum will be even higher. Unfortunately, the extent of FASD in South Africa is largely still unknown. Screening and diagnosing of a child after one year of age will increase the opportunity for support and suitable care that can lessen developmental delays and help discourage the mother from having further alcohol affected children (Rendall-Mkosi *et al.*, 2008). In American Studies conducted by Streissguth (1997), a high prevalence of disrupted school experiences,

trouble with law, inappropriate sexual behaviour, and substance abuse has been described for older children and adults with FASD. Even though exact prevalence rates have not yet been confirmed in South African studies, the high level of crimes and imprisonment among youth, risky sexual behaviour and an increase in drug abuse, should ring an alarm that undiagnosed and unmanaged FASD, may be contributing to these increasing rates (Rendall-Mkosi *et al.*, 2008).

A study was conducted on the West Coast of the Western Cape with five families each with more than one FAS child. The aim of the study was to determine what issues were faced when caring for a child with this disorder. It was reported that the FAS diagnosis had been made later in the child's life and that no education or support had been received to assist or help manage the children (Rendall-Mkosi, London, Jacobs & Morojele, 2008). A study conducted by Cloete (2013) showed that the majority of FAS children (54%) had left school in Grade 7.

## **2.3 DIAGNOSING FASD**

It is important to note that FASD is not a clinical diagnosis in itself, but rather an umbrella term that covers all disabilities resulting from maternal drinking (Beaton, 2005; Rasmussen, Horne & Witol, 2007). In decreasing order on the FASD continuum, FASD includes Fetal Alcohol Syndrome (FAS) which must include facial dysmorphism, growth delay and central nervous system abnormalities; Partial Fetal Alcohol Syndrome (PFAS) is diagnosed when it is confirmed that the mother has consumed alcohol, but the child does not present with all of the characteristics of FAS. Alcohol-Related Birth Defects (ARBD) is the presence of a variety of inborn irregularities. Alcohol-Related Neurodevelopmental Disorders (ARND) refers to small head circumference, brain structure irregularities, cognitive and behavioural problems (Stratton, Row & Battaglia, 1996). Even though FAS is the most detectable of the conditions it is believed that the milder conditions may be more widespread in general society. Streissguth and O'Malley (2000) found that it was difficult to diagnose the disorder on face based diagnosis and that not all children showed face dysmorphism (Rasmussen *et al.*, 2008). It is for this reason that the term FASD must be used to ensure that all dangerous effects resulting from prenatal alcohol exposure be acknowledged, documented and measured (Rendall-Mkosi *et al.*, 2008). The findings of a study of 50 children conducted by Rasmussen *et al.* (2007) showed evidence that there was brain dysfunction in all the children, but very few

showed irregular growth and/or facial differences. The findings were as follows; 92 % of the children showed no growth deficiency and 66% showed no facial dysmorphology.

### **2.3.1 The difficulty to diagnose**

Identifying persons who are affected by prenatal alcohol consumption presents a challenge to develop and apply effective FASD interventions. An example of this has been the on-going need to increase and expand FASD training to health care practitioners. Some medical staff may feel uncomfortable when questioning mothers as they do not have the necessary skills or strategies needed when questioning mothers about prenatal alcohol consumption. They may not have the ability to recognize features of FASD making it difficult, if not impossible to make a diagnosis or refer people to the correct resources for a diagnosis (Paley & O'Connor, 2011). Porty (2009) highlights some of her findings concerning the medical field and diagnosis. She supposes that medical staff work under the impression that light, sporadic drinking is not harmful to the foetus and that they are also cautious in speaking about FASD and diagnosing it. It is also known that FASD is often unnoticed and misdiagnosed due to other disorders such as ADD/ADHD and Tourette's sharing similar characteristics. Stigmatization may also play a significant role in preventing accurate assimilation of information or confirmation as to whether the mother drank whilst pregnant. They may be reluctant to share their alcohol intake out of fear of being responsible and judged for the child's condition (Paley & O'Connor, 2011).

### **2.3.2 The South African context of FASD**

As mentioned prior, for FASD to be correctly identified and diagnosed a large amount of human resources is essential. When one compares it to the diagnosis of other health issues such as Tuberculosis and HIV/Aids which can easily be completed by a single medical practitioner, it is easy to understand that the under-resourced FASD diagnostic services can give inaccurate or misdiagnosis (Rendall-Mkosi *et al.*, 2008). It is further complicated by the fact that the South African Constitution has no national overseeing protocols for screening and diagnosing Fetal Alcohol Syndrome or others Fetal Alcohol Spectrum Disorder's (Davies *et al.*, 2008). Screening for- and diagnosing FASD is challenging due to expert skills being both rare and expensive, as well as there being no clear screening tool that would successfully screen for all FASD conditions (Davies *et al.*, 2008).

Multidisciplinary teams are both costly and largely unavailable in South Africa (Rendall-Mkosi *et al.*, 2008). Also, since the diagnostic and support services are very limited in South Africa it is not known how many children utilize the various services available, and how many children who are found in youth correctional facilities and at mental health services are in fact children who suffer from FASD (Rendall-Mkosi *et al.*, 2008).

An option for increasing diagnosis would be to target health and education services in South Africa to screen for these disorders. If a child is identified or suspected of having FASD, he/she could then be referred to a multidisciplinary team for an official diagnosis (Davies *et al.*, 2008).

The earlier FASD can be identified the sooner intervention efforts can be implemented. Evidence shows that early identification serves as a protective factor against secondary disabilities. Families may become empowered by participating in and education schemes which provide support on how to provide for their children. How to maintain stable and nurturing households, conducive to their child's unique needs (Rendall-Mkosi *et al.*, 2008). This could in turn help to minimize or avoid adverse life outcomes by two- to four folds (Streissguth, Bookstein, Barr, Sampson, O'Malley & Young., 2004). It can also have a positive effect on the economy by teaching a FASD child to live productively within their means and to become an individual who contributes positively to society (Rendall-Mkosi *et al.*, 2008).

From the above it is clear that there is an urgent need for access and services which can provide an accurate FASD diagnosis in South Africa and in turn implementation of an effective intervention plan. It is however worrying at this stage, that even if a diagnosis is obtained, the affected individual and family often receive insufficient information on what FASD entails and how it is managed across the lifespan of the affected individuals (De Vries & Waller, 2004). A caregiver shared that having her child diagnosed with an FASD, was the last contact that she had with an institution and that she had minimal understanding of the child's condition (De Vries & Waller, 2004). Families initially experience a period of relief and optimism after their child is diagnosed only to find at a later stage, that such a diagnosis offers little help when long term management needs to be considered (De Vries & Waller, 2004). At present, even if a child is identified and diagnosed as an FASD candidate at an early stage,

the child does not automatically gain admission to essential intervention and treatment services which is almost non-existent in South Africa (Smith, 2003).

## **2.4 IMPLICATIONS FOR THE CHILD WITH FASD**

Alcohol is a strong teratogen and exposure to it during pregnancy may have everlasting effects on the unborn child. When this teratogen is present in the mother's bloodstream it can flow freely through the placenta into the developing foetus. The most effected parts of the foetus are the central nervous system and the brain. The amount of damage is reliant on factors such as gestational timing of alcohol, how often the mother drinks, the duration thereof, the amount of alcohol that is consumed and genetic factors of the biological mother, her socio-economic factors and her nutritional intake during pregnancy (Rendall-Mkosi *et al.*, 2008).

There is increasing awareness and agreement that FASD needs to be understood as an unseen and everlasting physical disorder with behavioural symptoms (Malbin, 2002). Individuals with FASD have substantial brain differences that give rise to this disorder. Because the brain damage is everlasting it cannot be outgrown and the biological effects cannot be cured (Rutman & Van Bibber, 2010). Steinhausen and Sphor (1998) described the impact of FASD on the individual as follows; "from birth onward, a chain of developmental hazards start to unfold".

Both animal and human studies conducted by Paley and O' Connor (2011) show that there is substantial changeability in the manifestations of prenatal alcohol exposure across individuals. Because of the heterogeneous characteristic of this disorder individuals with FASD will show different manifestations. Alcohol exposure can affect every system in the human body which means that caregivers need to keep a watchful eye on signs of problems as the child develops (The Edmonton and Area Fetal Alcohol Network, 2007). Each FASD individual will present with different struggles and unique strengths, learning styles and life experiences will also differ (Rutman & Van Bibber, 2010). Children are primarily affected by disturbances in attention, cognition, learning, memory, language, motor coordination, problem solving and abstract thinking. Each child will be influenced differently depending on the specific neurodevelopmental damage that has occurred (Premji, Benzie, Serrett & Hagden, 2006). These disturbances in the mental and behavioural handicap can result in severe social

and psychological consequences for the child and family. Therefore, there can be no doubt that FASD is a huge public health problem and that South Africa needs to give this matter urgent attention and act in a swift and decisive manner (Marais *et al.*, 2013).

### **2.4.1 Primary disabilities caused by FASD**

Prenatal exposure to alcohol can present the child with have lifelong challenges. The child can experience physical and neurological disorders, which in turn gives rise to serious problems with regards to daily functioning (Fast & Conry, 2004). Primary disabilities are a result of inherent functional problems of the central nervous system. These factors will subtly start to become more apparent as the child ages and development takes place (Whitehurst, 2011).

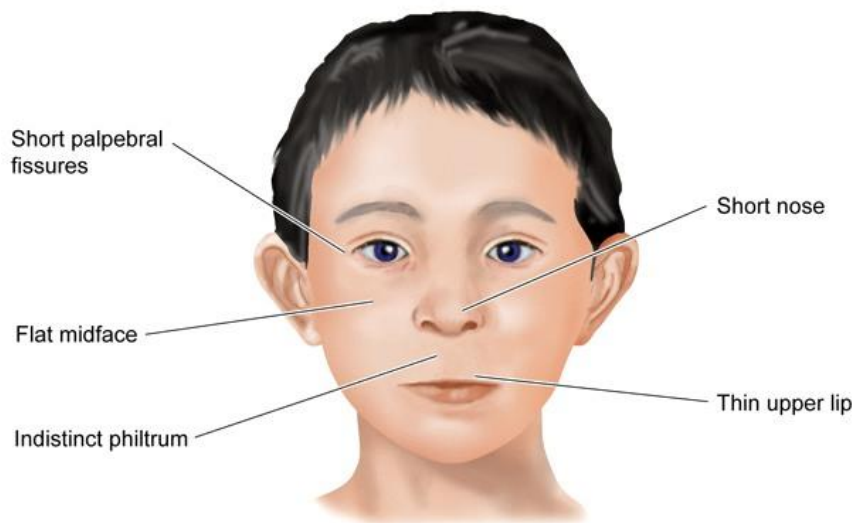
In order to understand the implications of primary disabilities for the affected child, this section will look at the four main functions that are affected namely; physical characteristics, mental functioning, behavioural challenges and learning difficulties.

#### **2.4.1.1 Physical characteristics**

The 3 main components of physical characteristics of FASD children are facial dysmorphology, growth deficiencies and damage to central nervous system (Thomas, Warren & Hewitt: 2010).

*Facial dysmorphology* that indicates FASD and more specifically FAS is caused by an underdeveloped mid-face and brain (Rendall-Mkosi *et al.*, 2008). Facial dysmorphology includes the following: short palpebral fissures, also known as narrow or small eyes in the horizontal level, a flattened mid face; thin upper lip and flattened philtrum, known as smoothened parallel ridges above the mouth. These abnormalities will be present at birth but will be most visible between the ages of six to 12 years. As a child enters adulthood these features become almost invisible due to the mid-line features that change as an individual ages (O'Malley, 2011: 2; Rendall-Mkosi *et al.*, 2008).

The following figure is a representation of facial dysmorphology that can be associated with FASD.



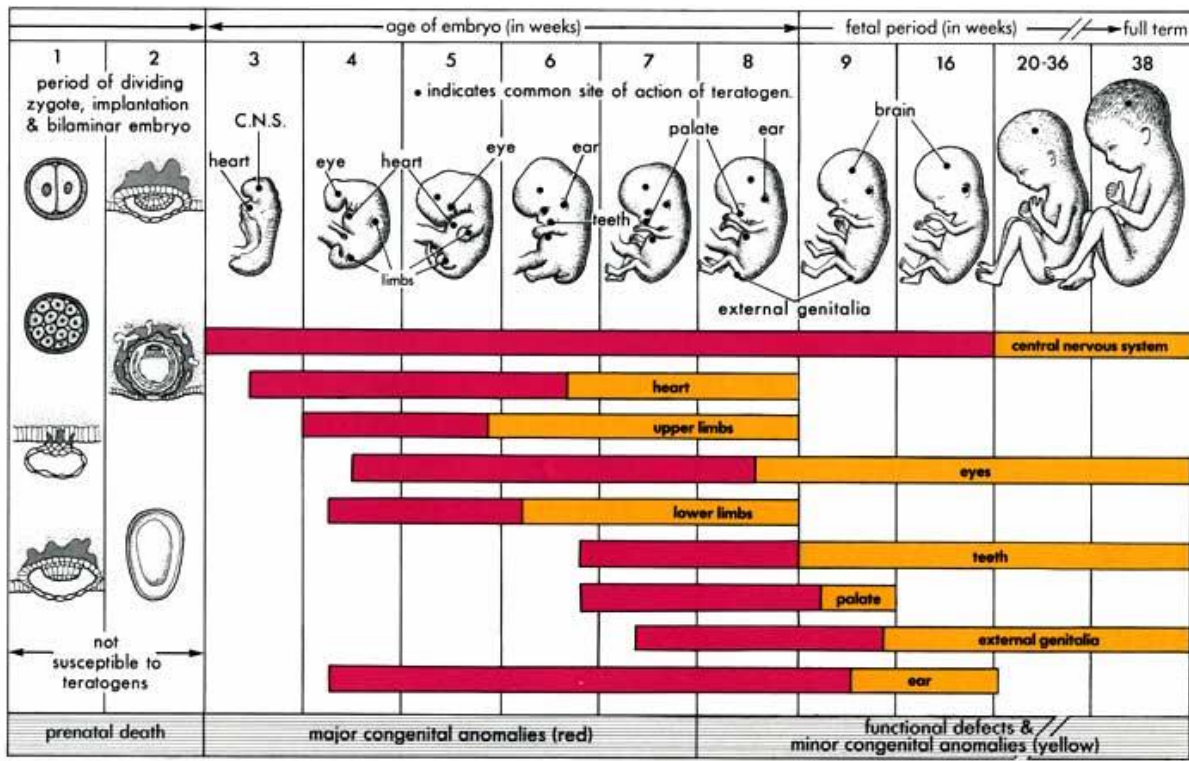
**Figure 2.1 Facial dysmorphology associated with FASD**

[Source: Duke University, 2014].

*Growth retardation* is often present with children who have been exposed to alcohol during gestation. FASD babies are often premature babies with a low birth weight. Growth is slow and children are often smaller in build and shorter in height compared to their peers (O'Malley, 2011). In addition to growth problems, prenatal alcohol exposure can also impact on other body organs. Damage done to body organs is directly related to what body parts were developing when the alcohol was ingested. The following organs of the body can be affected; the eyes, ears, teeth, heart, kidney and skeletal structure (O'Malley, 2011). These physical effects can be damaging to the general well-being of the affected child and may need medical and surgical intervention (O'Malley, 2011). The retarded growth and underdevelopment of the body is permanent even though it may move towards normalizing as the affected child reaches adolescence and adulthood. It is important to note however that the affected child will always be shorter, have a lower body mass index and have a smaller head than his/her peers (Rendall-Mkosi *et al.*, 2008).



The following figure represents the development of a foetus as well as the damage that can be caused by prenatal alcohol exposure during gestation.



**Figure 2.2 Development of foetus and genetic abnormalities**

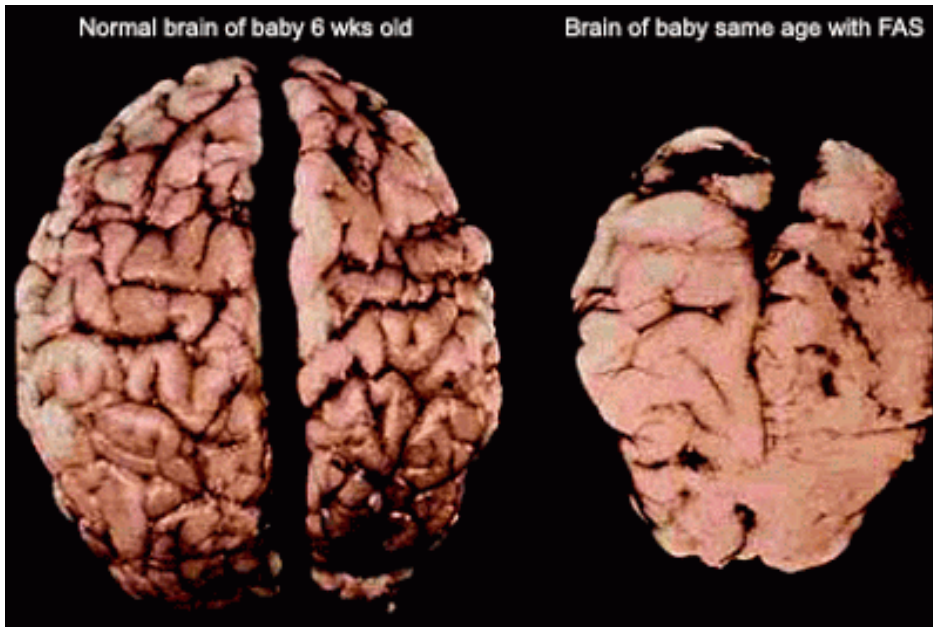
[Source: Ritchie, 2007].

*Damage to Central Nervous System* is probably the most detrimental to the child. Exposure to alcohol precedes changes to the developing brain which then causes lifelong irreversible damage. The brain is smaller in size compared to the brain of a non-exposed individual. This can be identified in the smaller head circumference of a child specifically visible with FAS (De Vries, 2012). Not only is the brain smaller, but in each individual case there can be specific structural abnormalities in the brain that will have certain complications with regards to the intellectual and behavioural functioning of the child (Rendall-Mkosi, 2008). Golden (2005) explained that alcohol exposure to the developing brain will cause abnormal development, the death of brain tissue and cause dislocation of certain cells, therefore not allowing optimal functioning of the brain. An increased space between the two



hemispheres of the brain can result in damaged or even absent communication patterns (Mattson & Riley, 1997; Kalberg, 2006, both cited in De Vries, 2012).

The following figure shows the differences between a brain exposed to alcohol and a non-exposed brain of six week old babies.

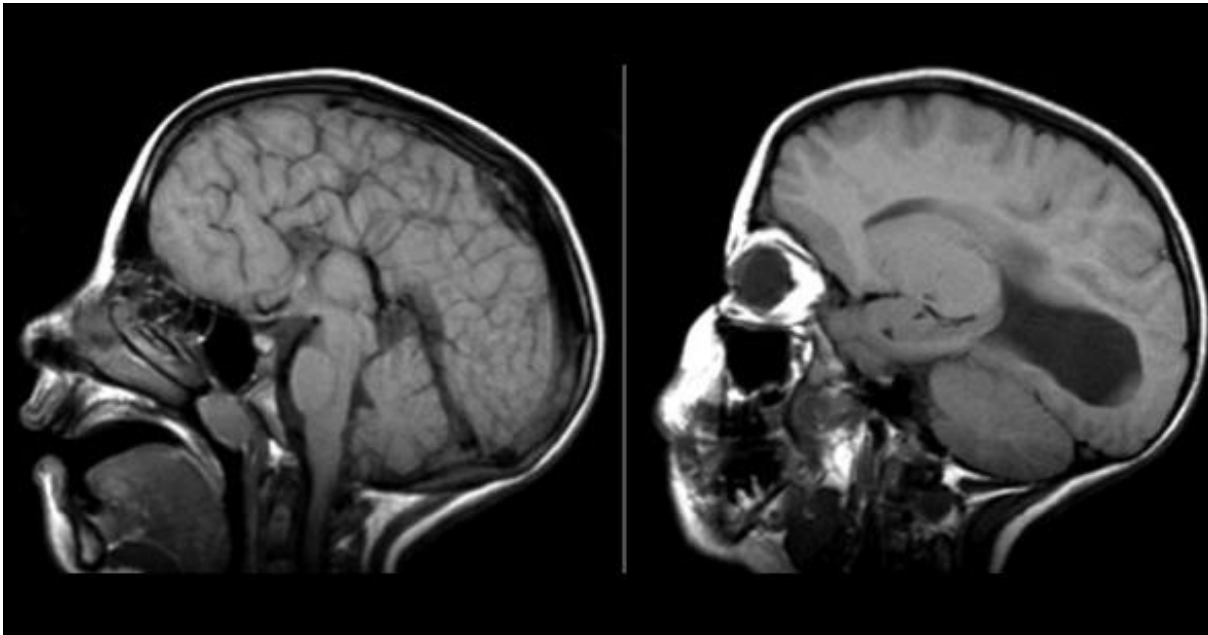


**Figure 2.3 Picture of normal brain compared to FAS brain**  
 [Source: Scream of Consciousness, 2007].

The following summary of brain alterations due to alcohol use was made by Kellerman (2006):

- *Frontal Lobes* which control impulse and decision-making and executive functioning.
- *Corpus Callosum* which is responsible for passing information from the left side (logic and rules) of the brain to the right side (impulse and feelings) of the brain.
- Reduction in size of the *cerebellum*- responsible for movement and memory.
- *Amygdala* which is responsible for recognition of faces, social conduct, understanding personal space, fear, aggression and education.
- *Hippocampus* that plays a role in learning and memory retention.
- The group of *Hypothalamus*, *Amygdala* and *Hippocampus* that together regulate emotional, social and sexual behaviour and empathy.

The following image is a side scan of the brain of a non-exposed child compared to an alcohol exposed child.



**Figure 2.4 Side scan of a normal brain (left) compared to an alcohol exposed brain (right)**  
[Source: Sandiego University, 2013].

It is important to note that even though the brain damage is not visible to the eye it does not mean that it does not exist. Rendall-Mkosi *et al.* (2008) explained that the change of brain functioning is best identified with the use of sophisticated imaging equipment. Regardless of being able to access such services, caregivers should be aware of the fact that it is inevitable that a child with FASD will have brain abnormalities, as this is the preceding factor for so many other challenges that makes the child unique. These primary challenges that are influenced by central nervous system abnormalities are mental functioning and behavioural challenges. This will be discussed in the following section.

#### **2.4.1.2 Mental functioning**

*Linking cause and effect:* FASD children can unintentionally find themselves in dangerous situations without thinking of the consequences. It is said that children with FASD do not learn from their experiences and that they are unable to understand the concept of cause and effect (Fast & Conry, 2004). This will often lead to behaviour that is not thought through which in turn can lead to problematic outcomes (O'Malley, 2011).

*Understanding:* Often children with FASD have trouble in understanding what they are shown or told. They do not always understand the need for social rules to be obeyed. It is quite common for children to accept rules and even verbally repeat them, but will turn around and break those exact rules that he/she supposedly understood. FASD children are not always able to adhere to rules because they may not understand the implications of disobeying them. Such children may not have the memory capacity to fully understand rules or adhere to them. FASD children are often not able apply the rules from one situation to the next or they truly believe that they are not bound by rules or that the rules do not apply to them (De Vries & Waller, 2004).

*Lack of capacity to think abstractly:* Children with FASD tend to think in concrete terms, for this reason problem solving is difficult. Statements made to them are taken up literally regardless whether it is true or not (O'Malley, 2011).

*Memory:* Children with FASD have irregular memory recall. They can also confuse or mix up details from a past event to the current one. Often there is confusion between the details of a real event with a fictional event (Fast & Conry, 2004).

#### **2.4.1.3 Behavioural challenges**

*Hypersensitivity:* Hypersensitivity can have vast implications for a FASD child. It can negatively impact on their learning abilities, attention span and their behaviour patterns (Weiner & Morse, 1994). Due to the hypersensitivity of affected children they become very easily overwhelmed in situations that are not controlled, the reason being that the brain needs to successfully process and manage numerous stimuli at one time (Weiner & Morse, 1994). When the ability to manage the incoming stimuli has been overloaded the child may break down, throw a tantrum or show frustration. When this happens it is vital that the caregiver remove the child from the source of stimuli and use calming techniques to help calm the child down. Hypersensitivity will also have a direct influence on eating habits of the child (Weiner & Morse, 1994).

*Maladaptive behaviour:* Individuals with FASD find it difficult to adapt to changing social environments and are ineffective in meeting required standards and acceptable norms in social settings (O'Malley, 2011).

*Attention-Deficit/Hyperactivity Disorder:* Children with FASD are also often diagnosed or suspected of having ADHD. This phenomenon is characterized by a combination of an inability to concentrate together with impulsive behaviour. The attention problems contribute to difficulty in school settings. In addition to the attention issues they often require additional learner support or supplementary help (O'Malley, 2011).

*Immediate gratification:* Individuals with FASD have an increased need for immediate gratification and they do not usually display the capacity to delay gratification. Understanding the concept of time is also scarce with many FASD individuals. The implications of the above can result in serious and very real challenges for them when they start working as adults. Such individuals are often unable to be on time for appointments; they are easily distracted from their duties and attracted to something more fun and exciting (De Vries & Waller, 2004).

*Poor impulse control:* According to O'Malley (2011), impulsivity is organically driven and very unpredictable. Children with FASD tend to show impulsive behaviour. Often reactions and behaviour are not regulated or self-monitored.

*Daily functioning:* Children with FASD may struggle to meet basic requirements essential to daily living. They may struggle with handling money, acquiring and keeping a job, to care for themselves and to use their leisure time in healthy and suitable ways (Fats & Conry, 2004).

*Vulnerability:* Children with FASD are at a heightened risk for vulnerability to peer pressure and environmental factors. FASD children have the need to fit in with the people around them and can easily blend into a group without understanding what such membership really entails. De Vries and Waller (2004) refer to this as 'moral chameleon'. It can even reach such levels that the child could belong to a gang or to a church group and both would be seen to be quite acceptable in his/her eyes.

*Unpredictability:* Children are not purposefully unpredictable. Such behaviour stems from the brain damage that has incurred much earlier. Behaviour shown by affected children can be enormously disproportionate to environmental stressors for example, a major crisis may have no effect on a child whatsoever but a minor misunderstanding can cause a big behavioural outburst (De Vries & Waller, 2004).

#### **2.4.1.4 Learning difficulties**

*Learning disorder:* Children who suffer from a FASD perform considerably worse in cognitive and adaptive functioning when compared to neuro-typical children without any disorder (Adnams *et al.*, 2001, cited in Paley & O'Connor, 2011). They show difficulty in many areas of attention, memory, intelligence and with decision-making skills. This impacts their ability to process and absorb information. They tend to miss large amounts of information if they do not receive special one-on-one attention within educational settings. Children also struggle with understanding goals and instructions that are only verbally stated and that are not supplemented with visual aids (Rasmussen *et al.*, 2007).

*Language:* Even though a child with FASD can develop a big and sophisticated vocabulary, they may not always have the ability to receive and understand informational content or express themselves appropriately in verbal and non-verbal ways (EFAN, 2007). This means that they will struggle to understand what you are saying to them and in turn also find it difficult to express themselves. They are not always able to tell you what they need or how they are feeling.

Organic brain damage that causes primary disabilities cannot be fixed or changed, but with support in example providing structure, stability, routine and supervision, the affected child may experience some success (EFAN, 2007).

#### **2.4.2 Secondary disabilities caused by FASD**

Whilst primary disability is a result of inherent functional problems reflective of central nervous system dysfunction, secondary disability is described as difficulties that develop over time, as the individual with FASD ages where an early diagnosis has not been acquired (Premji *et al.*, 2006; Brown *et al.*, 2007). Some specialists are of the opinion that individuals with FASD experience secondary effects due to the stress of not living up to the expectations of society (Brown *et al.*, 2007). According to Streissguth (2004) secondary disabilities are not present at birth and can be ameliorated through better understanding and relevant interventions with the affected individual. Caregivers have an important role to play by initiating interventions that can reduce secondary disabilities (Rutman & Van Bibber, 2010). Such disabilities can also be minimized or prevented through an increase in community awareness, professional understanding and deliberate and appropriate intervention

(Rutman & Van Bibber, 2010). The secondary disabilities include the following; mental health problems, disrupted school experiences, troubles with law, inappropriate sexual behaviour, drug and alcohol abuse, difficulty with independent living and difficulty with employment (Rendall-Mkosi *et al.*, 2008).

An international study conducted by Streissguth *et al.* (2004) with 415 FASD participants showed the following statistics with regards to the development of secondary disabilities. A total of 80% of the participants lived in alternative care, 61% had problematic school experiences, 60% of the participants had come into contact with the law and 50% had experienced imprisonment or have been kept in a mental health facility or program, 49 % had problems with inappropriate sexual behaviour and 35% struggled with substance abuse problems.

#### **2.4.2.1 Mental health issues**

The first and most common secondary disability is *mental health issues*. A study conducted by Ann Streissguth (1997) showed that 94% of the individuals showed mental disorders with clinical depression being most prevalent. Further issues include suicide attempts and threats, panic attacks, auditory and visual hallucinations. Mental health issues are likely to increase as the individual ages and no protective factors are available (Rendall-Mkosi *et al.*, 2008).

#### **2.4.2.2 Disrupted school experience**

Secondly, *a disrupted school experience* is very common amongst individuals with FASD. Children with FASD do not think and learn in the same manner as unaffected children and are challenged with unique factors which make basic learning especially hard. Due to their brain damage, children with FASD struggle to make sense of information in the same way as a neuro-typical child would. These unique factors include: weak short term memory, lowered IQ's, developmental delays and difficulty knowing whether they are reaching the required objectives. As the child progresses to higher levels, the challenges become more evident (Beaton, 2005). Many children affected by FASD do not officially qualify as "mentally retarded" and therefore cannot be placed in an appropriate school with the necessary resources and support (Rendall-Mkosi *et al.*, 2008).

Within a South African context, mainstream schools are supposed to accommodate children with disabilities within their community. However in reality, this is not the case. Educator's lack of accommodation and understanding of the unique needs of such children become most apparent in schools where teachers often do not have the capacity or skills to adapt their classrooms. They do not always make accommodations for the behavioural and educational challenges that the children face (Rendall-Mkosi *et al.*, 2008). In reality, very little support is available to affected children who cannot keep up with the volume and pace of work. Often classes at schools have up to 40 pupils, which is not conducive for one-on-one instruction that is needed for such a child to progress (Rendall-Mkosi *et al.*, 2008). FASD children are perceived to be uncooperative, difficult to manage and disruptive in the class. Unfortunately due to poor access and availability of resources, the on-going support that is needed cannot be provided unless the child is transferred to a special needs school. Such schools are also scarce in South Africa (Rendall-Mkosi *et al.*, 2008).

#### **2.4.2.3 *Trouble with the law***

Thirdly, *trouble with the law* is often a reality for individuals who are influenced by a FASD. Brain damage sustained by these individuals hinders their ability to exercise good judgment and they have difficulty understanding that there will be consequences for their actions. Abstract thinking and generalizing from one situation to the next is also a challenge. The affected individual is also very easily influenced and is often lured into and forced to participate in criminal activities because they want to 'fit in' (Marais *et al.*, 2013; Fats & Conry, 2004). A study conducted (Fats & Conry, 2004) estimated that 60% of those individuals diagnosed with a FASD, have had encounters with the legal system. Once they are involved in this system individuals face the challenges of giving statements and participating in their own defence. Lack of understanding of concepts such as 'cause and effect' makes them more vulnerable and often leads to false confessions, in the hope that the false confession will speed up the legal process, so that he/she may return home. An FASD affected individual is also prone to repeat a story as if it is his/her own (Fats & Conry, 2004). This shows that an FASD individual that encounters problems with law authorities needs to be offered a fair trial that takes the unique needs of such individuals into account.



Internationally, an increased awareness of FASD has resulted in various professions such as lawyers, judges, physicians and others to recognize that this disorder may be more prevalent in among the younger generation. Research indicates that FASD children are at a higher risk of developing maladaptive behaviour that can result in criminal activity (Fats & Conry, 2004). A study was conducted by Fast and Conry (2004) who pointed out that the universal 'legal system' has failed individuals with FASD. This is possibly due to these affected individuals being over-represented in prisons due to their vulnerabilities.

#### **2.4.2.4 *Inappropriate sexual behaviour***

*Inappropriate sexual behaviour* is another secondary disability that influences children with FASD. Because of their poor communication skills, social interaction might become more of a challenge for these children as they are vulnerable and often find themselves in abusive relationships. A study conducted by Streissguth (1996), showed that 39% of children with FASD showed inappropriate sexual behaviour. This includes sexual advances, sexual touching and promiscuity (Streissguth, 2004).

#### **2.4.2.5 *Drug and alcohol abuse***

*Drug and alcohol abuse* is also a secondary disability which is often developed by individuals affected by FASD, especially in households where high alcohol intake is accepted in the living environment and community. When a child affected by FASD is exposed to such norms, together with low socio-economic conditions, low educational level, poor judgment and a low self-esteem he/ she is likely to become involved in substance abuse (Rendall-Mkosi *et al.*, 2008).

#### **2.4.2.6 *Difficulty with independent living***

*Difficulty with independent living* becomes an issue when an individual suffers from FASD. Memory and problem solving skills are vital in order for one to conduct day-to-day responsibilities and to run a household effectively. This is often a challenge for affected individuals (Rendall-Mkosi *et al.*, 2008).

#### **2.4.2.7 *Difficulty with employment***

People with FASD have *difficulty obtaining employment* and if employed, one will often find they have the low paying, less skilled and menial jobs. In the South African context where jobs are already a



scarcity, the job opportunities for an individual with FASD are not very favourable particularly when characteristics such as low IQ, behavioural difficulties and social limitations are considered. It is of the opinion that individuals with FASD often have little opportunity to better themselves (Rendall-Mkosi *et al.*, 2008).

### **2.4.3 Protective factors against secondary disabilities**

According to Streissguth (2004), protective factors can decrease the risk of developing secondary disabilities up to two-four folds. Streissguth, Barr, Kogan and Bookstein (1997) identified the following protective factors which can help in preventing or minimizing the development of secondary disabilities: living in the nurturing and stable home, obtaining a diagnosis before six years of age, being protected from violence, minimal transition in households and living in each household for at least three years, living in a good quality home that has access to services for developmental disabilities and having basic needs met. One can therefore see that many people, services and organisations in society have a role to play in actively supporting children with FASD to prevent or minimize the impact of secondary disabilities in their lives. Weiner and Morse (1994) also showed that children with FASD showed less psychological symptoms when they were part of a stable environment.

## **2.5 THE FASD CHILD PLACED IN ALTERNATIVE CARE**

Pelech *et al.*, (2013) stated that there is an overall belief in welfare organisations that children of alcoholic mothers are better off when placed in alternative care. Traumatic and complex home situations are often detrimental to the general well-being of such children. The stability of an alternative care placement will increase the opportunity for the affected child to experience structure and permanency, which is vital in mediating against neurological difficulties that they will experience.

O'Malley and Streissguth (2003) conducted an international study and found that 80% of FASD infants and young children live in alternative placements, and that many of them have experienced more than one change, in where they were placed. It is clear that FASD children are over represented in alternative care settings (Paley & O'Connor, 2011). An international study conducted by Astley and Colleagues (2002, cited in Paley & O'Connor, 2011: 65) showed that the rate of FAS children was 10-

15 times higher in foster care than in the general population. Even though they are removed from their abusive environment in the biological home, children with FASD run the risk of experiencing disruptions in care giving relationships and adverse environmental challenges. A study conducted by McNichol (1999) on infants exposed to prenatal substance abuse, placed in family foster care had the following significant findings; there was greater need for health- and caregiver needs compared to other non-exposed foster children. These needs place additional demands on the foster family, foster care agencies and the medical community. An enlightened response in terms of awareness, training, access to services, follow through and application of appropriate interventions is required. This will mean that caregivers will also need the support of their family and will need to include them in training and support programs during foster placement of the influenced child (Blatt, Auerbach & Levy, 1997). Raising a child with FASD also requires time and cost considerations that are above those of raising a neuro-typical child (James Williams, Dubovsky & Merritt, 2011). Caregivers also need to accept the fact that the FASD child will remain in his/her care for a longer period of time than any other child (Soliday & McCluskey-Fawcett & Meck, 1994).

International studies show (National Organization on Fetal Alcohol Syndrome, 2002) only 1 in 3 children with FAS are raised by biological parents. The remaining 2/3rds are placed in alternative care. Another study conducted in Canada (2005) with 63 foster families showed that 63% were caring for a child who had a FAS diagnosis. It is important to understand that once a child is placed in foster care, they are subject to foster care placement breakdown and will more than likely experience multiple placements (Brown & Bednar, 2004). These placement breakdowns do not only negatively affect the child, but also affect the foster caregivers and the entire foster care system. This can result in a shortage of foster placements due to caregivers deciding that they no longer want to foster children in the future (Brown & Bednar, 2004). When these children are disrupted and moved around it also becomes extremely difficult to access adequate services and health care necessary help manage their disorder (Paley & O'Connor, 2011).

Smith (2003) explains that children who are removed from their biological homes due to abuse, neglect or any other reason are prone to experiencing lasting emotional scars, which can lead to impaired functioning socially and emotionally if it goes untreated. Clinical studies conducted by Smith

(2003) documented that psychological and behavioural problems are higher for FASD children when compared to neuro-typical children.

Foster and adoptive caregivers are usually unaware of the child's status when entering their household. When problems start arising, it can take many years before they arrive at an accurate diagnoses and answers as to what is causing the child's problems. These years of struggling can have a tremendous effect on affected families. Often when no solution is found, the only option is to remove the child from their care. The child is then removed and placed with another family where the same process will likely follow. It will seldom happen that the underlying cause of the child's behavioural challenges will be understood and worked on (Major Ryan, Doreen, Bonnett, Callie & Gass, 2006). Olson, Oti, Gelo and Beck (2009) agrees by saying that a child with FASD that has unmet needs and absent intervention will have devastating outcomes for all the parties involved. Unfortunately studies show that families with a FASD child mostly find services to be scarce, that professionals have a lack of understanding and adequate social support is generally unavailable (Paley & O'Connor, 2011).

Families will only be able to offer optimal care for the affected child once they are aware of the nature and severity of the disorder they face (Banks, 2003). Children with FASD are often not anti-social on purpose, intentionally disobedient or wilfully disruptive. This behaviour is often as a result of permanent brain damage that they sustained in the developmental stages of life. This brain damage hinders the manner in which they process information from their surroundings (James *et al.*, 2011). Caregivers will try to make use of typical parenting methods thinking that the child will learn through experiencing the consequences of their actions. If caregivers do not have a clear understanding of the different brain functioning and the complexities that these children face, they will find their parenting methods unsuccessful. If this continues, the caregiver may become frustrated and angry and the child will be perceived as wilfully defiant (James *et al.*, 2011). Culture also plays a vital role in how the disorder is viewed and responded to. How a family views the disorder will determine to what extent the family is impacted and what nature of applicable intervention will be sought. The manner in which the family is prepared, the attitudes they have towards the diagnosis and the social support that is available will determine how they will respond to the child (Banks, 2003).

Child care agencies are often unaware of mothers' alcohol use during pregnancy or do not think that it is a determining factor in the rest of the life of the child. For this reason they do not inform the prospective foster caregivers about it. Unfortunately foster caregivers may never then consider this to be a possible reason for the child's problems. A study done by Whitehurst (2011) also showed that caregivers are purposefully not informed that the child is affected by prenatal alcohol exposure before they adopt/ foster a child. When the challenges associated with FASD start surfacing at later stages, confirmation of prenatal alcohol use becomes difficult, if not impossible. Therefore many children with FASD stay undiagnosed or are misdiagnosed with disorders such as ADD/ADHD (O'Malley, 2011). Caregivers find it difficult to gather information about the foster child and his/her disorder. Participants in a study (Brown *et al.* 2007:325) indicated they "had no information about the child" and "did not know what was wrong with the child" when placement was done.

Unfortunately there are challenges with regards to provision of appropriate social services in South Africa. Regardless of guidelines set out by the Children's Act No. 38 of 2005 (Republic of South Africa, 2005) that professional reports need to be compiled and submitted by a designated social worker, family advocate, psychologist, medical practitioner or any other qualified person in order for a children's court hearing to be opened, these reports still lack in providing thorough background information regarding the concerned children. The circumstances of the child and the circumstances of the caregiver need to be investigated thoroughly so as to write a well-informed report. Service providers in this field do generally not strive to gain a thorough background of each child that is placed in alternative care, placing the child in situations where caregivers do not understand them or understand what their particular needs are.

There are however, caregivers who are motivated to care for children with special needs. Such motivating factors will differ from the one individual to the next. Motivating factors can include the following: the desire to see a child improve and change, to nurture and care for a child with multiple challenges, to have a child when not otherwise possible, feeling responsible because of a lack of suitable placements, or to help a child because he/she is in need and the family is financially well-off and lastly because they want to help to keep the child connected to their families and communities (Brown, Sigvaldason & Bednar, 2006).

## **2.6 CHALLENGES FACED AS A RESULT OF FASD CHILD ENTERING THE HOUSEHOLD**

Caregivers who take care of children with developmental disabilities such as FASD will experience challenges in various areas. In the following section four of these challenges will be discussed.

### **2.6.1 Education for a child with FASD**

FASD children suffer in academic and social situations due to the damage to the brain that hinders their ability to engage as needed and as society expects. Even for children on the milder end of the FASD continuum will show different learning needs and performance from their neuro-typical class peers (Olswang, Svensson & Astley, 2010). Children with FASD have trouble with retaining and recalling information, learning often occurs in spurts. Such children need to be in specific learning settings and taught using visual and activity based methods. It is also difficult for them to apply information learnt in one situation to another. They often “miss” general social cues such as facial expressions, voice tone and gestures that usually help us to identify and show proper behaviour in daily situations (Weiner & Morse, 1994). They require extra attention and one-on-one support and for a teacher with more than 20 pupils this becomes almost impossible (Kalberg, May, Blankenship, Bukley, Gossage & Adnams, 2013). According to Kalberg *et al.* (2013) there are some challenges for children with FASD: understanding the curriculum, keeping up the pace and being able to work individually and in groups. There is a lack of structure in classrooms; children may find it difficult relating to and mingling with other children in the class (Beaton, 2005). Also absent in the classrooms, is the opportunity for additional and learning supports (Kalberg *et al.*, 2013). Learning is also heavily influenced by hyperactivity often displayed by FASD children (Weiner & Morse, 1994).

Many caregivers are faced with the challenge of having to educate teachers and school managers about the challenges that their child face and how they are negatively impacted when they do not receive the appropriate educational attention. Caregivers are forced to work together with the school in order to maintain consistency of practice that will help the child cope in such a setting. It is vital that caregivers communicate unceasingly with the school in order to plan and strategize with different teachers so that the affected child keeps learning and building up a positive self-esteem (Brown & Bednar, 2004).

A caregiver shared the following:

*"I think that there is a tendency for people to overestimate the abilities of people with FAS. They think and perceive that someone will be able to understand what they are being told and able to follow instructions and sometimes it just isn't so... It's not a matter of not wanting to; they're just not able to"* (Rutman & Van Bibber, 2010: 358).

### **2.6.2 Keeping the FASD child involved in society and public**

Caregivers have stated that it is a challenge to keep their FASD children involved in the community. They become frustrated with the lack of activities such as aftercare and leisure activities where children with FASD can get involved. These children find it extremely challenging to be part of and continue to participate in existing school or community activities given their lack of social skills (Brown & Bednar, 2004). Children with FASD often become isolated due to these difficulties where they will be exposed to neuro-typical peers and the watchful eye of the public. Literature (Brown & Bednar, 2004) refers to problems of social skills, weak interpersonal skills, emotional problems, conduct problems and social development that are displayed by the affected child. Caregivers also shared that their FASD children showed instinct related problems such as aggression. In addition to this, the child is at risk of placing themselves and others in unsafe situations due to an absence of fear (Brown & Bednar, 2004). FASD children often exhibit inappropriate behaviour due to the fact that they cannot appreciate the consequences of their actions. This can cause them to blur differences between public and private behaviour and do things that are viewed as unacceptable and embarrassing. Children may be perceived as being deliberately defiant or causing problems when in actual fact, it is a direct result of their disorder (Weiner & Morse, 1994). As the behavioural problems continue and grow it often becomes a reality that a child will become alienated and exploited (De Vries & Waller, 2004).

Making friends can be a great difficulty for an affected child as a result of the brain damage and not understanding important social customs or subtle cues used in friendships. Children may show no understanding of the idea of personal space which may cause people to feel uncomfortable or annoyed (Beaton, 2005). Due to developmental delays FASD children may also show less maturity than other children of the same age making it difficult for them to communicate effectively. This may result in the affected child becoming the target of teasing and bullying (Beaton, 2005).

Public places can be daunting for children with FASD as it can be a source of over-stimulation. This can cause a child to become irritated and act out. It is almost a given that a child will have a meltdown in a crowded place if not prepared sufficiently. Temper tantrums often draw attention in these public places and this is often a source of embarrassment and frustration for caregivers, especially when people who do not grasp the effects of brain damage on the child's daily functioning and then think that caregivers are at fault for the child's melt down (Beaton, 2005).

### **2.6.3 Adapting the household for the FASD child**

Caregivers consistently describe that by changing and restructuring the environment of the child positive outcomes will follow. Hinde (1993) suggested that caregivers who care for children with FASD should be willing to adapt their home settings. She further discusses that the two most prominent factors to change for optimal success are as follows: caregivers should show preparedness to adjust their lifestyles and make necessary changes in their routines that will help the child succeed and secondly, provide the child with a positive atmosphere in which they work towards focusing on the child's strengths that are identified instead on focusing on what the child does wrong (Weiner & Morse, 1994).

### **2.6.4 Dealing with new and continuous behavioural problems**

Being the caregiver for a child with FASD is distinctly different from any other care giving role that can be experienced. Children's problem behaviours tend to appear in unreasonable, unanticipated and very intense ways (Porty, 2009). Caregivers need to be prepared to deal with the sometimes unpredictable and difficult behaviour of children with FASD.

Beaton (2005) reminds caregivers that in caring for FASD children the focus should be on changing the environment and not the child. FASD is a lifelong disorder and will not go away. Caregivers need to remember that the brain damage is permanent. This can make management of behaviour more challenging. Difficulties experienced by the child include: difficulty in paying attention and ability to focus, hyperactivity and an increase in temper tantrums. The most significant behaviour problems that were reported by participants in a study completed by Brown *et al.* (2007) were a lack of impulse control, aggression and increasing need for attention. Olswang, Svenson and Astley (2010) explained

that FASD children struggle to build relationships due to the fact that their behaviour is so unpredictable at times. Porty (2009) explains that caregivers continually feel off balance, never being certain whether the child is truly incapable or just disinclined to learn appropriate behaviours.

Bad behaviour is often a result of over stimulation and caregivers need to remember that children are not always mean and bad on purpose. Trying to parent them in these situations and responding with normal parenting techniques does not usually work with FASD children. Dealing with them requires a lot of patience, consistency, understanding and redirection instead of correction. A parent shared the following: *“Remember, it is not that they won’t. It’s that they can’t”* (Beaton, 2005: 5).

Parenting a child with FASD is a lifelong commitment because the child can never grow out of the disorder. The caregivers will need continuous support throughout the lifespan of their child in order to understand and support the child in overcoming difficulties and to build on their strengths (Davies *et al.*, 2008).

## **2.7 IMPLICATIONS FOR THE CAREGIVER**

During interviews with caregivers of FASD children, Rutman and Van Bibber (2010) found that they face a number of challenges due to: the conditions that they need to live in, the negative societal attitudes that they experience as well as a lack of support provided to them through welfare policies. A South African study conducted by Chirwa (2012) with mothers of physically and mentally disabled children showed that the main source of support was from friends and family and only a very small percentage of participants received support from welfare organisations. Caregivers also experience incredible disapproval from other people as they work towards finding support for their child in order for them to grow (Porty, 2009). They explain that they are unable to access support that is needed and end up becoming consumed with managing crises on a daily basis (De Vries & Waller, 2004). The experience of each caregiver is unique but none the less very challenging at times. Some of the following implications may be experienced: emotional conflict, continuous setback, high levels of stress, exhaustion, caring for self, need for respite services, a battle for support, forever parenting, taken for granted and feeling unappreciated, keeping and making plans, loss and grief, fear and



hopelessness and feeling judged by others. These implications will be discussed in the following section.

### **2.7.1 Emotional conflict**

Caregivers of FASD children responded (Whitehurst, 2011) that they experience various emotions and that life often feels like a continuous battle fought on behalf of their child. Fear and nervousness is also often experienced by caregivers. Olson *et al.* (2009) explains that FASD carries an emotional factor due to caregivers feeling that the disorder could have been prevented. James *et al.* (2011) further explains that caregivers are often unprepared for the big investment that needs to be made financially, emotionally and physically in order to provide the child with necessary support to develop properly. Due to this unpreparedness, increased feelings of anger and frustration towards the affected child may develop and a heightened risk for abuse becomes a reality.

A caregiver indicated that although she first experienced an inability to accept her child's diagnosis and implications thereof, she was later able to accept the situation and move towards seeking strategies to assist her. Other caregivers also shared that their lives had turned out completely different to what they initially thought after adopting such a child (Walls & Pei, 2013).

Children affected by FASD can often be destructive when they are left unsupervised which forces the caregiver to keep a watchful eye on their child at all times. This can be incredibly exhausting and if caregivers do not have the vital resources to assist them, they can be pushed to the limit (Porty, 2009). As a caregiver, this can be incredibly difficult as the intention is to care for your child to the best of your ability, however they can't help but feel frustration and anger due to the circumstances they face. The battle to deal with the emotional conflict and mixed emotions in addition to try and hide it from the child becomes incredibly hard to manage (Porty, 2009).

### **2.7.2 Continuous setbacks**

Caregivers shared that they continuously face the challenge of anticipating the child's behaviour in order to prevent problems before they occur. It is stated over and over that children with FASD can show inconsistency in their behaviour when the contexts and days change. Another contributing factor is the challenges in memory retention FASD children struggle with. A study conducted by Cloete

(2013) with South African carers of FASD showed that 45% of their children showed difficulties in retaining memory and knowledge. This poses the challenge of preventing setbacks even for caregivers who are more experienced in supporting their child (Brown & Bednar, 2004).

### **2.7.3 High levels of stress**

Children with FASD show significant cognitive, behaviour and emotional challenges which can be enormously difficult for the caregiver to manage. It is generally accepted that caring for a child with brain damage involves high levels of energy, can be time consuming, requires the completion of difficult and unpleasant tasks and can also result in regular disruption of family schedules and activities which can lead to increased levels of stress (Plant & Sanders, 2007). Paley *et al.* (2006) also showed that caregivers reported very high levels of stress associated with the care of FASD child. This can result in undesirable consequences for the entire family (Paley & O'Connor, 2011; Plant & Sanders, 2007). High levels of stress can further increase the risk of family maladjustments with other extended family members (Turnbull & Ruef, 1996).

Support needs to be made available for these caregivers in order to equip them with strategies to adapt and improve their parenting strategies and increase self-efficacy. This in turn will help to foster a positive relationship with the affected child (Paley & O'Connor, 2011).

Stress within the caregiver can also result from the high need for medical care and mental health problems of child, economic implications and the exhaustion of increased need for management (O'Malley & Streissguth, 2003). Caregivers are continuously visiting their local clinics to meet the needs of affected children. Caregivers are faced with high demands of special care for their child who may cause significant disruption in family life and also result in high levels of stress. The care demands persist throughout the life stages of child and it is necessary for the caregivers to continually adapt to developing stresses and crises (Floyd & Gallagher, 1997). Belsky (1984) agrees by proposing that many sources of stress will affect parental functioning and that the consideration of events related to their caregiving duties will have an effect for the entire family. In example, a caregiver that experiences great levels of stress could be at risk for negative outcomes such as fragmented parent-child interactions, lack of fulfilment with caregiving, less ideal functions as caregiver, lower child development ability and a heightened risk for child abuse (Soliday *et al.*, 1994). Paley *et al.* (2006) also

explains that caregivers who experience high levels of stress and are not able to manage it, can contribute to the worsening of the child's difficulties. This highlights the importance of developing programs that support caregivers with management of stress.

#### **2.7.4 Exhaustion**

Due to the fact that FASD children require continuous attention and have high levels of need, caregivers may build up tension in themselves which in turn affects their relationship with the child and other members in the family. As this tensions build up, caregivers start feeling drained, emotionally and physically (Brown *et al.*, 2007). Exhaustion will follow if caregivers are not able to take a break or have the internal and external resources to help deal with such tension. Figley (1995) speaks about 'Compassion Fatigue' that caregivers experience as a result of prolonged exposure to stress as a result of feeling deep sorrow and compassion for another individual. As a result of not being able to alleviate the experienced disability or to be released of the responsibility of experiencing compassion stress, caregivers of FASD children are at a higher risk of experiencing compassion fatigue. Figley (2002) further explains that in addition to exhaustion, compassion fatigue can result in a sense of helplessness, isolation, and dramatic changes in the functioning and lifestyle of the caregiver. South African participants of Chirwa's study (2012) shared that there was a big need for assistance in helping them to be able to take time off and rest from their caregiving role to children with physical and mental disabilities.

#### **2.7.5 Caring for self**

Caregivers often share that caring for a child with FASD is an intense and challenging reality. With each FASD child being different in the challenges they face, caring for their needs may cause caregivers to feel exhausted, overcome, and frustrated. When caregivers are involved with a child with brain damage, it is easy to constantly put their needs above your own. 'Moral proscription' is the word that is used to describe this (Shearn & Todd, 2000). The caregiver will continually feel that it is his/her duty toward the child and the family, to sacrifice his/her own needs and wants in order to be a good caregiver. Guilt is often experienced when they are unable to meet the 'requirements' and 'special duties' needed.

It is vitally important that caregivers take care of themselves in order to take care of others. Beaton (2005) explains that the better caregivers look after themselves the more eagerness and drive they will have for their affected child. Connecting with other individuals who understand FASD and sharing of experiences will enable them to relate to each other and allow them to vent when it is necessary. These opportunities will contribute to positive outcomes for the caregiver. It is very important for caregivers to build up support for themselves as caregivers, and for their families (Beaton, 2005) in order to ensure self-care.

### **2.7.6 Needing respite care**

Due to the high demand for constant supervision and specialised care, caregivers of children with FASD can become exhausted and will need rest. During respite care, caregivers are relieved from their duties in order to take time for themselves and relax as well as to do the tasks that they normally do not get around to doing. Due to the demands of caring for a child with alcohol related brain injuries being continuously challenging, taking respite becomes vital. Giunta and Streissguth (1988) warned that without respite, caregivers would get overtired, over worked and would eventually burnout (Brown & Bednar, 2004). According to Jones (1999) respite is one thing that will allow caregivers to maintain the physical and emotional nurturing skills that they need to optimally care for their FASD child (Brown & Bednar, 2004). Respite will also allow caregivers to make time for themselves and ensure self-care. Caregivers are challenged with keeping up with the internal and external demands of parenting a FASD child which necessitates high energy and vigilance. Respite is also viewed as a solid coping strategy to help caregivers when it is most needed (Brown & Bednar, 2004). Even though respite is viewed as a necessity it is difficult to find someone to take over caregiver duties and who has the sufficient knowledge on FASD. A caregiver shared that children with FASD do not transition well and that it takes time for a respite worker to be welcomed and accepted by the child. Respite care is not recognized in South Africa as a profession or provided service and many caregivers often have to rely on family members or friends to help them with respite or they do not take respite care at all (Walls & Pei, 2013).

### 2.7.7 A battle for support

FASD is a complex disorder which requires the caregivers to be able to access multiple support services to meet the variety of care needs of the child. Each child will need different kinds of services in response to their unique needs and life phase. Caregivers have reported that there are currently many obstacles in accessing these services (Walls & Pei, 2013).

Caregivers from international studies shared that there was a general lack of knowledge amongst professionals regarding FASD and that the support available to them was generally lacking. When it was available it was often fragmented and not holistic in nature (Whitehurst, 2011) and they had to endure long waiting lists for these various services for example participation in parent support services, skills training and life skill programs (Walls & Pei, 2013). A caregiver shared her experience of being on a waiting list for the relevant services for over 18 months. When she was finally able to access the services her child was too old and no longer qualified for them. A second caregiver reported that they stopped accessing support services due to the fact that the staff turnover was so high that the child never had the opportunity to build relationships with the staff, and that this negatively impacted on the support experience (Walls & Pei, 2013).

As mentioned before, in order for an affected child to succeed there are a number of support structures that need to be put in place. This can result in a big burden being placed on caregivers to organize this (Olson, Oti, Gelo & Beck, 2009). Ryan *et al.* (2006) shared that due to missing attentiveness and acknowledgment of FASD, affected individuals and their families are often referred to inappropriate services or are rejected based on not meeting the requirements needed to qualify for a specific service. This is even worsened when the child displays no facial features or has an IQ that is not below average. For these families that are seen as having a child that is “normal” it becomes frustrating because they are aware of the neurological issues the child face, which decreases their level of functioning (Major Ryan *et al.*, 2006). Caregivers also shared that even when there were services available: professionals ignored the reliability of their own knowledge and skill that has developed through rearing an effected child (Brown & Bednar, 2004). No family exists in a vacuum and for families with disabled children it becomes difficult when alterations need to be made and in

dealing with social labels which often hinder their ability to gain formal and informal support (Banks, 2003).

### **2.7.8 Forever parenting**

Caregivers of FASD individuals are faced with the possibility that they will have to parent for the rest of their lives and that planning for the future even beyond their own old age is difficult (Olson *et al.*, 2009). Caregivers who care for children with intellectual disabilities experience unique stresses and worries about how their child will manage to live independently one day and whether or not the child will need on-going care and support throughout his/her adult life (Floyd & Gallagher, 1997). In order for an adult to function independently, they need the ability to think abstractly and if a child is not able to do this, day to day living may become a challenge. An example of being able to think in abstract terms is to work with money. Rent needs to be paid, transport needs to be arranged and food needs to be purchased. These simple daily tasks become a major stumbling block and affected children generally have poor skills in their ability to manage these tasks. Thus, they struggle to become independent adults (EFAN, 2007). This means that caregivers will have to continuously intervene and help put structures in place that best cater for the needs of the FASD individual. A South African study (Cloete, 2013) of caregivers with FAS children found that all participants stated that they would provide care for their children on a permanent basis and that the affected children needed to feel security of their future. A study conducted by Rowbottom, Merali and Pei (2010) described how non-biological caregiver's first visions of raising a child to be fully self-reliant and an independent adult could be lessened by the reality of long term care-giving.

### **2.7.9 Taken for granted and feeling unappreciated**

Caregivers often feel unacknowledged and disrespected when in contact with care systems and professionals. They have shared that they feel like professionals look down upon them because of their struggle to maintain control of situations and of their affected child. This can have very negative effects on a caregiver, who often gives everything they have to care for the child. They also experience negativity when in contact with extended family members and the larger community (Brown *et al.*, 2007). It is apparent that caregivers feel that their gained knowledge from working with

the child is disregarded and not used by professionals. Caregivers gain a great deal of knowledge and yet feel that their opinions and experiences are unappreciated (Brown & Bednar, 2004).

### **2.7.10 Keeping and making plans**

Caregivers can often not anticipate what behaviour and progress their FASD child will show and this makes it very difficult for caregivers to set short term and long term goals for themselves and their child. Planning ahead becomes very difficult for caregivers when they think of their child needing to become independent one day (Brown & Bednar, 2004). Many caregivers experience isolation due to the fact that they are unable to ensure that their appointments are kept and that they can't always make commitments especially when faced with challenges. Many caregivers are not able to maintain friendships or make new ones because of the unpredictable nature of their caregiver role. Caregivers also struggle to find babysitters that are skilled and willing to supervise their children whilst they are out. When caregivers and their children experience difficulties in the company of friends, caregivers find it difficult to cope with the suggestions and comments made by their friends. Caregivers insist that no one truly understands what they struggle with daily (Porty, 2009).

### **2.7.11 Experiencing loss and grief**

Loss and grief are two very common and important experiences that caregivers of FASD individuals face in their lives (Porty, 2009). Caregivers of FASD children may experience a deep sense of loss and grief surrounding the prospects and visions that they had for the child that has now been stripped away as a result of the disorder. This grief can result in long-lasting "sorrow for what will never be" (Peljert, 1996). This is brought back continuously when the child changes from one developmental stage to the next and what the child is expected to reach when compared to other children of the same age (Burke, Hainsworth, Eakes & Lindgren, 1992). O'Brien (2007) speaks of "ambiguous loss" that caregivers experience when their affected child shows little progress. Within this there is hope of the child being cured or misdiagnosed. Feeling guilty about not living up to the ideal standards of being a 'good parent' who provides a happy normal childhood for the disabled child is also a reality for many caregivers (Burton, Lethbridge & Phipps, 2008). Caregivers also experience a loss of leisure time and loss of self, due to constantly being consumed with the child. It is clear that caregivers are significantly impacted by their child's disorder (Porty, 2009).

Many children are placed with biological grandparents who resume the responsibility of caring for them. When the disorder comes into play, these caregivers will often experience a sense of loss due to the fact that the idea of their “care free” retirement no longer exists and that they are facing some of the most challenging caregiver roles for the rest of their lives (Porty, 2009).

### **2.7.12 Experiencing fear and hopelessness**

Porty (2009) explains that caregivers of FASD children are aware of secondary disabilities that pose a threat to their child. Even though doing all that they possibly can to prevent them from developing the secondary disabilities, fear is experienced about the prospects of the uncertain future the child has to go through. In fearing for the child’s future many caregivers start experiencing hopelessness. That feeling of ‘you just do not know what to do any more’. Caregivers have to start looking at living day-by-day and have to focus on trying to believe that they can and must endure the challenges that they are faced with. But on some days hope is just much less reachable (Porty, 2009).

### **2.7.13 Feeling judged by others**

Caregivers of children with FASD are vulnerable to feeling judged by ‘outsiders’ who do not understand their child. These caregivers interpret comments made by people as obstructive and unhelpful. In addition to caregivers already feeling sensitive to public’s reaction to their child’s behaviour which might be unpredictable at times, judgmental stares and one-size-fits all parenting approaches escalates the feeling of being judged (Porty, 2009). When caregivers experience these ‘outsider’ comments and unhelpful advice, it often enhances their own feelings of hopelessness and frustration. Caregivers of mentally and physically disabled children in a South-African study conducted by Chirwa (2009:174) stated that they experience feelings of withdrawal and isolation. One of the respondents explained the following:

*I get frustrated when I cannot help my son with something especially when we are in public. So I tend to isolate myself from other people as I do not want them to be judging me or questioning why my child is like that.*



## 2.8 IMPLICATIONS ON OTHER MEMBERS OF THE FAMILY

Research shows that other family members within the household can also be affected by the FASD child. Stovall and Dozier (1998) shared that foster parents often need to deal with issues related to their own biological family who do not always understand the need that the child may have. Emphasis is placed on the biological children of caregivers. Part (1993) shared that caregivers' own children are often impacted when a child enters the household. This impact can range from gaining a great deal of positive experience to feeling a sense of displacement.

The Department of Health and Human Services of the United States (2006) speaks about various challenges siblings can go through as a result of the FASD children in the household. Biological children may not understand why the FASD child is treated differently especially if they look normal. Jealousy over attention that is given to the affected child can also surface. They may also experience loneliness because they feel like they are the only ones struggling with a sibling that is disabled and lastly, feel burdened because they also have to assist in caring for the child.

## 2.9 CONCLUSION

Constant self-sacrifice involved with caring for a FASD child as well as constant setbacks and disappointments can result in 'learned helplessness' and ultimately, family breakdown. It is extremely important that intervention strategies be made available to caregivers in order to prevent burnout and help them towards finding the strength and strategies needed to help their child develop and gain a sense of balance and belonging in society (Porty, 2009: 47-48). Brown and Bednar (2004: 15) agree by stating that informal and formal support systems play a significant role in how well caregivers will cope in caring for their affected child. Efforts should be made to provide caregivers with resources and support.

Giunta and Streissguth (1988:458) explain the important consideration for caregivers of FASD affected individuals:

*The caretaker of a child with FAS assumes a responsibility far beyond that normally associated with parenting. The constellation of physical, intellectual, and behavioural characteristics that*

*typifies patients with FAS can create a very demanding situation for a caretaker. These patients often require constant supervision they are described by successful caretakers as requiring an extraordinary amount of time, energy, love, and, most of all, consistency. These caretakers need support in their efforts.*

From the above information, it is clear that caregivers who take on the responsibility of caring for children with alcohol related brain damage are in need of an incredible amount of support that can guide and assist them in their task of providing the best care possible whilst maintaining a life that gives them satisfaction and joy.

## CHAPTER 3

# THE UTILISATION OF SUPPORT GROUPS IN ORDER TO CARE FOR THE CHILD WITH FASD

### 3.1 INTRODUCTION

As reflected in chapter two it is clear that there is a great and ever increasing need for caregivers of FASD children to access support structures. Marcellus (2010) stated that an increase in the complexity and multiplicity of the needs of children in alternative care, are necessitating a more sophisticated and reinforced support system for caregivers. For alternative care families to remain a complete unit they must learn to manage the physical, emotional and behavioural challenges the child faces in addition to dealing with friends, family, school systems and professionals who do not yet have a good understanding about FASD and the implications it entails (Kortla & Martin, 2009).

Non-biological caregivers are in the honoured position of endeavouring to create a stable environment that can help the children to succeed in the light of their uniqueness. This is however, frequently impacted by outside judgement of their parenting skills, possibly due to a lack of knowledge on FASD and an inadequate understanding of how to deal with its manifestations on a daily basis. As challenges increase, the trials experienced by caregivers will negatively affect their family environment and wellbeing (Rowbottom *et al.*, 2010). Support and interventions are thus crucial in preventing this.

Within this chapter, investigation into the role social workers play in supporting caregivers of FASD children is explored. Specific references are made as to how non-biological caregivers access and utilise support groups. For the purpose of this study a mutual aid approach and educational approach to support groups are viewed as two relevant approaches used in dealing with the unique challenges these caregivers face. Perceived positive and negative aspects that exist around being part of support groups are also covered. The primary emphasis will thus not be on the theoretical underpinnings of group work but more on the experiences and utilisation of support groups by non-biological caregivers. The following main themes will be discussed: the need for support, types of available

support, gaining support, the social work response, the group work method, types of groups, the support group, approaches to group work and the positive and negative aspects of support groups.

### **3.2 THE NEED FOR SUPPORT**

As the health, social and developmental needs of FASD children are more complex, caregivers are required to develop a skill base of specific knowledge to effectively address these needs (Marcellus, 2010). In addition to the medical needs, children who enter alternative care are also at a heightened risk of experiencing severe trauma, and will have special needs that most placements are not prepared for. It is consistently shown that children receiving foster care have an increased chance of having chronic medical conditions (Marcellus, 2010). Due to this fact caregivers need to develop specialized skills to work effectively with these children and therefore, a clear need for support is identified.

Floyd and Gallagher (1997) assumed that the usage of services assist in reducing the stress and care demands placed on caregivers of FASD children and that the greater use of services, would result in less overall stress as opposed to not accessing support at all. It is therefore incredibly important for service providers to understand exactly what the needs of the caregivers are in order to provide them with relevant opportunities to grow and to become more empowered (Whitehurst, 2011). Caregivers can further be assisted by receiving assistance in making necessary changes to their daily living routines and households, to ensure that they provide their FASD child with a good quality and stable home and to minimize or even prevent some secondary disabilities from developing (Olson *et al.*, 2009). Caregivers can also be assisted to become advocates for their children through utilisation of support services, this being the platform from which they gain relevant information and encouragement. Olson *et al.* (2009) further states that these same support networks will improve interaction styles, decrease many forms of stresses related to FASD. It may help to improve the self-worth and abilities of caregivers who can then run their households more strategically, which could prevent placement breakdowns from occurring (Brown *et al.*, 2007). Such preventions will allow caregivers to feel more competent in their own ability and to ensure positive development for the affected child (Giunta & Streissguth, 1988).

Once caregivers have adopted a more positive outlook they will become more practical and realistic about the challenges they face and how to overcome them. This will enable them to focus on the positive characteristics of their affected child and channel their energy into building and maintaining long term, well suited care plans for their child (Brown *et al.*, 2005).

Brown *et al.* (2007) stated that education through community support services gives caregivers the ability to increase their personal knowledge and skills, which also results in recruiting and retaining caregivers who are willing and able to successfully care for children with FASD. In contrast, caregivers not receiving support may blame themselves for the affected child's problems (Weiner & Morse, 1994).

A study conducted by Brown *et al.* (2005) reported that caregivers have an increasing need to share, and to obtain guidance and support from other caregivers who experience the same living conditions as they do. Wilton and Plane (2006) agreed by saying that peer support is crucial in decreasing stress and increasing resilience in families affected by FASD. Families are also less prone to feeling isolated when they are in contact with other families who share their predicament.

Unfortunately, even though children spend more of their time with caregivers than with any other role player in the welfare system, caregivers are least equipped and supported in their responsibilities due to lack of available and relevant programs that support and educate them. This continues despite the rise in prevalence rates across the world (Marcellus, 2010). Marcellus (2010) further states that understanding the complex role caregivers play, treatment strategies should be developed in order to ensure that the voice of caregivers are represented within decision-making processes.

### **3.3 TYPES OF SUPPORT AVAILABLE TO CAREGIVERS OF FASD CHILDREN**

Caregivers may receive support in various forms and levels in society. Aronson and Hagberg (1998) further this by giving examples of such forms: support can be provided through peer mentoring relationships and counselling by professionals and advocacy groups. According to their findings peer relationships were most effective as it provided the caregivers with support for emotional issues, helped them gain more information regarding the disability of their child and showed them how and

where to gain professional help. Support can also be divided into formal and informal systems (Perry, 2013).

*Informal support:* According to Perry (2013) informal social support is emotional and/or physical help obtained from those close to individuals such as immediate family, friendship circles, neighbours or extended family members. It can also be provided for by larger bodies such as social organizations and religious communities (Soliday *et al.*, 1994). Support from informal networks does not always come easy and there are often issues especially with extended family members regarding the FASD child. It might be helpful if caregivers can be assisted to learn to cope with and deal with such challenges more effectively. Extended family members can also be included in intervention programs which might enable them to support their affected families better (Perry, 2013).

*Formal support:* This type of support is provided by professionals. It includes: educational programs for the FASD child, family interventions such as family counselling, respite care that enables caregivers to rest, behavioural management training and caregiver support groups (Perry 2013). Beaton (2005) suggested that general discussions on FASD provide a great opportunity for caregivers to reach out to others in a similar situation, to gain enriching insight and to link up with other relevant supportive networks. Some of the participants of his study explained that “a light went on” when they attended a conference about caring for FASD children for the first time. Perry (2013) however makes an important suggestion from her findings that even though services were offered, caregivers had sometimes found it to be in conflict with their own values and that it failed to meet their unique needs. For this reason she suggested that services need to be flexible and sensitive to the self-identified needs that caregivers and their families share. Some caregivers in the study formed their own support groups. Others, made use of internet support groups. Thus, it is known that being in contact with other caregivers who have a child with a developmental disability provides an irreplaceable support system and that caregivers support groups may be extremely helpful (Perry, 2013).

### 3.4 GAINING SUPPORT

Caring for a child with FASD can be very rewarding. However, there are days that require more patience, creativity and energy. There are days when caregivers feel frustrated, isolated and alone due to their unique situation. The need to share their needs and experiences with other people in the same situation becomes vital. Gaining access to such support networks can be a wonderful way to expand their knowledge, because of the opportunity to learn from others, to discover new methods of parenting and to simply share how you feel. Unfortunately, such support networks are scarce particularly if you live in rural communities (Beaton, 2005). An international study conducted by Olson *et al.* (2009) in Seattle showed that 63% of 52 non-biological caregivers of FASD children shared that their need to discuss their experiences and feelings about the affected children with others in a similar situation, was unmet. Very little is known on the experiences of South African caregivers on gaining support for their unique needs.

Crucial to successful adaptation is the ability for affected families to gain access to these appropriate support services. They may help families manage the child's needs, and also decrease disability-related problems such as secondary disabilities. Even though basic services are provided, caregivers must usually make extra efforts to pursue additional and sometimes vital services (Floyd & Gallagher, 1997). This is further complicated by the fact that many support networks do not make provision for FASD. Often children with FASD are in need of too much support to be accepted in "mainstream" services. Often, a lack of a clear diagnosis and a high IQ score exclude FASD children from qualifying for "developmental disability" services (Porty, 2009). Floyd and Gallagher (1997) state that caregivers will utilize services based on their own motivation for assistance. Such motivation for the need for assistance will be directly related to the understanding of the nature of the child's disability. Walls and Pei (2013) conducted a study on looking at available systems of care in Canada. Their participants shared that there was a great need for services that were more aligned to the support of caregiver needs. Easier access to existing services and endeavours to meet requirements for individuals affected by FASD is also needed.

### 3.5 THE SOCIAL WORK RESPONSE

Social work is a profession that supports and works for the well-being and development of all people irrespective of where they come from or what their current position is. Within the social work profession, workers are able to respond to and deal with various single, group and public problems with the aim of improving the social functioning, coping abilities and resilience of those individuals involved (Konopka, 1983).

In today's society, social workers deal with overwhelmingly exposed children and families. Non-biological caregivers often feel overcome by their circumstances and feelings of helplessness when dealing with the challenges related to FASD. These individuals are further affected by the lack of provision and assistance that is made for them by their families and surrounding community. Physical, mental, emotional and social weakening becomes a reality as they face day-to-day challenges of caring for children affected by FASD. When the resources within themselves also start to decline, they become exceptionally vulnerable to isolation and burnout (Gitterman & Shulman, 2005).

There is a clear and ever pressing need for the social work profession to take further responsibility to assist caregivers with their challenges of caring for a child affected by prenatal alcohol exposure. Social work professionals are trained and therefore have the professional capacity to help families develop and maintain stable and nurturing households, which is conducive to the needs of FASD children (Kortla & Martin, 2009). Social workers can therefore assist caregivers to develop realistic expectations of their child. They can help create home environments that support their affected child, as well as guide them on how to teach their child, social skills and behaviour guideline techniques, that are vital to daily functioning (Kortla & Martin, 2009). Giunta and Streissguth (1988) agree by stating that professional support will empower caregivers to advocate for their child and themselves. This will in turn help prevent feelings of incompetency and the overwhelming desire to give up. It is important to remember however, that these supportive relationships are reciprocal in nature, and that the professional needs to view the caregiver as an expert in understanding their own affected child better. Without mutual respect, the process will not be effective and the desired outcomes and objectives will not be achieved. Social workers are thus challenged to display professional competence, identifying complex needs, designing family services and support networks through their



professional conduct (Malone, McKinsey, Thyer & Straka, 2000). They should develop and exercise new skills and abilities, demonstrate and acknowledge the families strengths and resources (Malone *et al.*, 2000). Konopka (1983) is viewed as a seminal author of group work. He supposed that the worker must use his/her professional capacity effectively through helping group members become self-sustaining, help to assist each other and ultimately influence the social system of which they are a part. This is achievable through the utilisation of the special skills taught in social work and the application of sincere, authentic and skilled working relationships.

Within the following section group work as a method of social work intervention will be highlighted. Types of group work are then identified with emphasis on support groups as an effective type of group in helping non-biological caregivers of FASD children. Approaches to support groups will then also be discussed.

### **3.6 THE GROUP WORK METHOD**

Human beings are entangled in each other lives and Konopka (1983), stated more than two decades ago that not one human being can live optimally detached from others. For the emotional, physical and intellectual development of an individual to take place human relationships are vital. These human relationships are found in family settings, friendships and other social groups. The group experience is a learning experience. As a group member acquires new skills within the group context, these skills are then applied in other areas of their lives and ultimately teaching individuals to exercise more control over their lives (Brandler & Roman, 1999; Reid, 1997; Toseland & Rivas, 2009).

Group work can be viewed in the following light:

*Groups work because human beings have the capacity to process information, to learn from experience and example. Above all, they work because they have some success in allaying suspicion of new and different ideas, in overcoming resistance and anxiety about alternative ways of behaving and by providing support and understanding from others with similar experiences, difficulties, dilemmas and problems but having different methods of coping. What gives a member of a friendship group a sense of being accepted and able to relax in the company of peers is the same factor, which can give the individual member of a group the sense*

*of being free and well enough supported to try new, different and potentially more effective ways of thinking and behaving (Douglas, 2005: 8-9).*

According to the influential work of Konopka (1983) group work aims at humanizing services offered to individuals with a common goal. Within this method of work, members are encouraged and supported in the development of their social functioning, which in turn will empower them to manage their personal and communal challenges more successfully. Garvin *et al.* (2004) agrees by stating that group work allows for individuals to gain greater control and mastery over their personal environments.

Gitterman and Shulman (2005) states that group members will potentially develop greater individual, relational and environmental control in their lives when they are able to impact and assist each other in a give-and-take manner. Citron, Solomon and Draine (1999) found in their study with caregivers that the most positively perceived method of learning new perspectives was through the small group process. It can be a cost effective method to help caregivers assume their unique roles and responsibilities. They are also provided with an opportunity to express their feelings without fear of humiliation (Johnson & Johnson, 2009; Northen & Kurland, 2001).

### **3.7 TYPES OF GROUPS**

Various types of group work were considered for this research study. They include: *therapy groups* that aim to help members cope with or better individual problems, or rehabilitate themselves after social or health difficulties. *Treatment groups* aim to assist members in meeting their social-economical needs. *Task groups* are aimed at accomplishing tasks, produce a product or carry out a mandate (Hepworth, Rooney, Rooney, Strom-Gottfried & Larsen, 2006; Zastrow, 2013). *Self-Help groups* aim to bring people together who share a particular need, problem or concern so as to offer social and emotional support. Group members share a personal connection in the concern and usually avoid professional guidance in favour of lay guidance with the aim of achieving their special purpose (Segal, Gerdes & Steiner, 2013, Zastrow, 2013). *Social action groups* aim to attain social change through the establishment of local constituencies so that partakers can view themselves as influential so that changes can take place on prominent issues and that power can be reallocated (Segal, Gerdes

& Steiner, 2013). *Recreation groups* aim to offer participants with events for pleasure and exercise. These groups are mostly unstructured in nature and seldom have a leader (Zastrow, 2013). *Counselling groups* are mostly consisting of members who are undergoing severe emotional or personal issues. The goal of such a group is to explore problems in depth and then develop one or more strategies for solving them. Facilitators of such groups necessitate extensive skill, discernment and understanding of human behaviour (Zastrow, 2013).

Lastly, *support groups* are prominently used with individuals who are undergoing crises and need help in facing it. It provides a chance for participants to share their experiences and find support and relief among others who comprehend their situation from first-hand experience (Segal, Gerdes & Steiner, 2013). The following section will focus on support groups as a type of group work.

### **3.8 THE SUPPORT GROUP**

By utilising a support group, group members are provided with an opportunity for strategy and success sharing which can improve efficacy and strengthen social support systems that caregivers so desperately need. Social workers are in a unique position to initiate and facilitate such opportunities (Kortla & Martin, 2009).

Kortla and Martin (2009) further state that caregivers can acquire much needed information through support group participation. In these groups, the opportunities for sharing successes and strategies is provided for and by doing this self-efficacy will be increased. According to Butler and Wintram (1991) support groups serve significance in the following ways: as a source of immediate support where the knowledge that the meeting will take place regularly is a safety net in itself; serves to be a place where shared experiences are valued and recognised; providing a way for isolation and loneliness to be broken; serves as a place where different perspectives can be shared on how to deal with personal problems and lastly it is a place where power can be experienced over personal situations, and possible ways to change them.

International cases in which such support groups have been established and utilised have been recorded and non-biological caregivers have benefitted from them (Bertrand, 2009). General feedback included reduced isolation, non-judgemental environments, peer support, normalisation of

their own personal issues and stress, mentorship, education, practical help, overall support and a general investment in seeing their respective families succeed (Porty, 2009). Hagen and Gallagher (1997) found from their international study that participants also perceived benefits of support groups in the following ways: they were educated in acquiring resources, challenged on ungrounded guilty feelings, they were provided with ways to form barriers against exhaustion, and they felt nurtured and were provided with the opportunity to vent in a confidential environment. Caregivers who joined a support group generally regarded themselves highly satisfied compared to caregivers who had not been part of such a group. Those who had greater social support were able to feel more content in their parenting roles and have more successful placements (Soliday *et al.*, 1994).

A Canadian study was conducted by Porty (2009) in which non-biological caregivers of FASD children were asked about what types of the support in the group context was most helpful. Their response can be divided into two themes namely, emotional support and practical support. The following section will be an analysis of her findings. It is important to note that the South African context may differ from the findings of Porty (2009). The following section will be divided into emotional support and practical support.

### **3.8.1 Emotional support**

#### **3.8.1.1 *Absolute respect and non-judgmentalism***

Group members shared that they were placed within a supportive environment where they received unconditional acceptance and support. This was a place where they could be themselves without being questioned or criticised for their fears and feelings. They were able to speak about taboo topics without feeling judged, which was a relief from the usual disapproving contexts they were used to.

#### **3.8.1.2 *Reciprocal relations to other caregivers***

Group members shared that they often required social support as their friendships with caregivers of neuro-typical children faded. Group members found it frustrating when their friends offered them advice. They showed a lack of understanding of FASD and were thus perceived as being unsupportive. Within the support groups, group members were able to make instant connection with other people who understood and supported them. They appreciated the fact that their feelings of isolation and

helplessness became less and that they experienced newfound support. One of the group members shared that the support group provided courage in a time of disaster. It was an encouragement when their peers would walk beside them and journey alongside them. Even though not one of the participants experienced the same circumstances, they could provide strength and understanding without expecting lengthy explanations from each other.

#### **3.8.1.3 *Normalization of circumstances***

Group members shared that they were able to find that their intense feelings of stress and frustration was not as abnormal as they thought. In sharing their feelings, they found that others felt the same. It was found that a new 'normal' existed for caregivers with FASD children. It was a relief for many caregivers who saw the raw emotions of their peers and knowing that they felt it too.

#### **3.8.1.4 *Enabling of significant emotional progressions***

It often occurs that caregivers have to accept the reality that their child is affected by a disability. Caregivers need to decide whether they believe it or not. There is often also not a final diagnosis, which can further increase the caregivers' denial. When other participants share their experiences about their FASD child, the doubting carer will either be able to relate or not. This process will help the process of working through their doubts and facing the resulting emotions. Group members can move from complete denial to a point of acceptance and a willingness to face their new reality. The experiencing of grief was also shared when members heard the stories of others. This provided for an opportunity for discussion and progression.

### **3.8.2 Practical support**

#### **3.8.2.1 *Enabling for a change in thought-patterns regarding FASD***

Caregivers in Porty's study (2009) repeatedly said that they changed their views about FASD and how their understanding and tolerance regarding their child's behaviour had increased. This process however was not an easy one, and the support of fellow caregivers was viewed as critical. Caregivers needed to be reminded constantly that they needed to generate change, especially in periods where the child seemed normal again and doubt about FASD came to the fore.

### **3.8.2.2 *An opportunity for respite/rest***

Group members admitted that it was a relief to be able to break away from the reality of caring for an FASD child for the few hours when they were away to participate in the support group. They were able to participate in a social environment without having to feel guilt-ridden.

### **3.8.2.3 *Linking to resources***

A key theme emerging was the fact that group members were provided with the opportunity to find out more about relevant and available resources outside of the support group. Other group members or the social worker could give them guidance on where to find the best resources for their needs.

### **3.8.2.4 *Advocacy within caregiver support groups***

Group members indicated that they continuously supported and enabled each other, to continue to persevere in acquiring relevant services even if it meant repetitive requests, pleas or pressures of legal action. Group members were able to encourage each other and walk side by side in dealing with important matters. The teamwork mind set also allowed the group to advocate through bigger efforts such as awareness days, conferences, research studies and media projects.

### **3.8.2.5 *Innovation and training***

Some of the group members of Porty's study (2009) pointed out that they were involved in speciality groups that covered specific topics relevant to their situations. Specialist speakers would be invited and asked to share their findings and their resolutions with the caregivers. Such topics would include justice issues, health issues and educational issues and how these difficulties can be overcome by making changes that would be conducive to the FASD child.

### **3.8.2.6 *Practical tools***

A support group provides the opportunity for helpful ideas to be exchanged as to help caregivers in their carer role. Group members are useful resources for each other, as they share practical tips on what works and what does not. Practical resources would include, visual aids, helpful picture symbols to visualise rules and schedules, movies, books and conference resources.

### 3.9 APPROACHES TO SUPPORT GROUPS

Two approaches, namely the mutual aid approach and educational approach were identified as most applicable for the objectives of this research study. An *educational approach* has the primary focus of enabling members to learn more about a common issue and a *mutual aid approach* helps individual members gain a sense of personal, interpersonal and environmental control over their lives (Hyde, 2012). Both approaches will be discussed individually in the section below.

#### 3.9.1 The mutual aid approach

Choosing to work with a mutual aid approach is preceded by the aim of empowering group members to be in a position of accessing help as well as being a source of help to others (Steinberg, 2004). Schwartz (1961, cited in Garvin *et al.*, 2004) was the first to introduce the term and further explained mutual aid as alliance of individuals that need each other and the professional worker. Within this context, helping systems are implemented to work on common life issues, interests and tasks. This approach to group work is distinguished from others by making use of supportive intervention strategies and by helping members cope with stressful life events and enabling members to enhance their coping abilities for current situations as well as future situations that might be stressful (Sulman, 2009; Toseland & Rivas, 2005).

Not only is mutual aid a process but an outcome as well. In order for it to become an outcome, group members need to have the capacity and opportunity to communicate and interact with one another, when they feel they have something to contribute within this process (Shulman, 2009; Steinberg, 2004). When someone realizes that another person experiences a similar circumstance, the sense of alienation is reduced. It entitles a person to move beyond their mere feelings to a more objective understanding and finally a resolution. Sharing feelings allows for individuals to test validity thereof, and for their ideas to be considered or accepted by others. Through this process, the person receives and in return gives to others. The self-worth of group members will increase as they see that they have something valuable to give to others (Bradler & Roman, 1999; Gitterman & Shulman, 2005).

A *mutual aid climate* is achieved in the following ways:

*Restoring of balance* can only be achieved once members are willing to express their true feelings and accept the ideas and feelings of others. The aim is to *achieve an atmosphere where all group members have the freedom to express themselves* without the fear of being judged by others whilst also having the willingness to listen to the opinions of their fellow group members with an open mind. *This climate is generous* but also moderated by the call for seriousness at times when common issues that initiated the start of the group come to the fore. Within this context, there also *needs to be equilibrium between the need for comradeship and the need to express independence and uniqueness*. *Creativity and the ability to interact* within a group atmosphere are necessary for a mutual aid climate. Members of the group must show the willingness to brainstorm on all possible outcomes and options for action, no matter how unlikely it seems. *Structure balanced with flexibility* is also essential to mutual aid climate (Steinberg, 2004).

### **3.9.1.1 Primary functions of mutual aid groups**

There are three primary functions to working with groups from a mutual aid approach which will be discussed next.

*Harnessing strengths:* Instead of focusing on limitations and what group members have lacking, the aim is to focus on what is positive and uplifting, such as the attributes, skills and capacities the group members possess. Every individual will have something positive that works in their favour and by helping them to realize this; they will be empowered to apply these skills in a manner that helps them develop positively (Steinberg, 2004). Another important consideration is that all group members need to be viewed as human-resources. This will allow for authority in the group to be shared and for all members to experience the freedom in contributing and taking from the group experience as they are able to and as the need arises (Gitterman & Shulman, 2005; Steinberg, 2004).

*Group Building:* Group building is the process in which a sense of 'we-ness' is developed. This is achieved in assisting group members recognise those matters, needs, wishes and objectives which will bind them as a community (Steinberg, 2004). In order for group building to develop positively the



following two tasks are crucial: every occasion should be utilised to identify and indicate all the similarities that the groups share and group autonomy should be encouraged as much as possible through the sharing of leadership functions with the group members. This is achieved through allowing the group members to take responsibility in making decisions even when they assume that the group leader has greater understanding on the topic (Shulman, 2009; Steinberg, 2004).

*Teaching Purposeful Use of Self:* This process intends to prevent individuals from participating in situations where mere advice giving is achieved. Often people are not receptive to it which makes it useless. Individuals in the group need to be able to achieve the ability of thinking about their own life experiences and then also being able to talk about them. Through the sharing of stories, good and bad, members find ways in which to be helpful to other. By re-examining their past experiences, group members will have the opportunity to celebrate their achieved success as well as having the opportunity to learn new skills as they reflect, revise and consider less successful stories (Steinberg, 2004).

### **3.9.1.2    *The nine dynamics/Processes of mutual aid***

There are identified undercurrents determining whether or not a group enables mutual aid between group members. The following nine dynamics were identified for the purpose of this research study in order to investigate how the group worker can identify whether or not groups support a shared climate.

#### ***(a)    Sharing data***

From the first session group members need to understand that their knowledge, wisdom and experiences are crucial to group development and ultimately the overall success. This will allow for the process of self-reflection and identification of personal strengths that they are willing to share with the group. They ultimately are enabled to begin to see themselves as 'data resources' (Steinberg, 2004). Members are important resources for each other as they share relevant data (Garvin *et al.*, 2004). They provide each other with important facts, ideas and beliefs that they themselves have benefited from whilst dealing with FASD children. Whilst the content of data sharing can vary from one group to the next, the fact that individuals of a group can learn from each other through information sharing is key (Gitterman & Shulman, 2005). Only once they experience the value in being

able to share and receive, being the helper and being helped, will they take ownership of the group process (Steinberg, 2004).

The social worker should understand the importance of allowing group members to express feelings that are so often hidden away (Brandler, 1998). The social worker should also remember that they themselves have information and knowledge that needs to be shared with the group in order to participate in data-sharing process. It is important however that this own knowledge is not forced or seen as superior to group knowledge (Steinberg, 2004).

### *(b) The dialectic process*

Gitterman and Shulman (2005) describe the dialectic process as one where the members develop an idea, an opportunity is provided for the idea to be challenged and all group members are then allowed to form their own opinion regarding this. Group members serve as sounding boards for their fellow members and an opportunity for new views to be accepted and new ways to be acquired. This is an important factor considering that non-biological caregivers have expressed the need to talk to others in the same situation. The dialectic process develops as group members share their experiences on life issues and concerns. Members have the opportunity to discuss, argue and challenge each other in order to gain a clearer understanding (Garvin *et al.*, 2004). In order for the debating and sharing of true information to take place the group must be perceived as safe and free of judgement. As valuable as debating is, it can be a very sensitive matter. It may be difficult through the way in which members may be afraid to share their true feelings due to the fear of being judged or being alone in a situation or others may experience difficulty in saying what they really want to say without offending someone (Steinberg, 2004).

### *(c) Discussing taboos*

As challenging as it can be to participate in straightforward talk, it becomes even more difficult when group members approach topics they describe as taboo. This can be difficult even in situations we see as simply social (Steinberg, 2004). According to Gitterman and Shulman (2005) taboos are those unstated norms of behaviour in society that forbids honest discussion of fears and concerns. People often joke about taboo subjects but talking about it in a serious light is forbidden. Talking about forbidden subjects might be more acceptable for some members and they may experience the

urgency to discuss this more than the rest of the group members. When they voice these forbidden taboos, other group members see the bravery of these members as accepted and supported by the social worker or group members. This provides the rest of the group the opportunity to build their own courage to do the same. Discussing taboos will also allow dormant feelings that are viewed as inappropriate to come to the fore. When others in the group speak of the unspeakable challenges such as inappropriate sexual behaviour their FASD children exhibit it allows for members to express their own experiences regarding this.

Steinberg (2004) highlights the fact that taboo subjects are usually what the formation of groups are based on. Thus entering taboo terrain is vital. The social worker can help this process along by modelling the process by showing the groups how you as the worker view their wants and fears and how this can be met through participation in the group. This process can also be helped through the way in which the worker ensures that members understand that the current group will be different from groups which they are used to. Even though this unique process can at times be hard, the outcome is aimed at addressing all issues useful to the helping process (Steinberg, 2004). As members learn to discuss taboo issues and find the courage to voice things they have buried a long time ago the mutual aid amongst the group deepens (Garvin *et al.*, 2000).

*(d) All in the same boat*

It is important for group members to learn early on that by being in the same boat as their fellow group members will not necessarily prevent them from going anywhere, but that by being in the same boat places them on common ground and provides the opportunity for their strengths to also be in that same boat (Gitterman & Shulman, 2009; Steinberg, 2004).

As members listen to each other, they realise that they are not alone in the way they cope and react to their experiences or that they are the only ones who struggle with the challenges of caring for a FASD child. Others are in the same boat as them and the feelings that they experience are not as abnormal as they thought. People are often released of incredible feelings of guilt and destructive thought patterns when they learn that others experience the same as them (Garvin *et al.*, 2004).

Healing takes place when someone realises that someone else feels like they do, that someone else shares their frustration, uncertainty and all the experiences they do (Gitterman & Shulman, 2005). A study conducted by Hyde (2012) shared that the group members primarily found it most helpful to interact with others who were in “the same boat as them”. They were able to feel supported and could put faith in their peers and in the group process.

#### *(e) Mutual support*

One of the most important aspects of mutual aid is the need for provision of support, care and empathy between the members. It is developed through the emotional commitment that is made by group members within themselves, in each other and in the group as a total. Mutual support does not mean that group members will always agree on topics, experiences and viewpoints but that comfort can be sought in the fact that group members will try to understand each other’s viewpoints (Steinberg, 2004).

Mutual aid is nurtured through the sharing of regular life struggles. Only when group members begin to understand each other and their experiences in a true and deep manner are they able to show true mutual aid towards each other (Garvin *et al.*, 2004). As group members build enough courage to share their challenges they become each other’s mutual support through direct and indirect efforts to provide understanding and support. This enables the person sharing to feel more able in carrying their burden and dealing with it. *“Having peers try to share in your painful feelings can be experienced in a form of a gift, and be much more meaningful than artificial efforts to cheer you up.”* (Gitterman & Shulman, 2005: 23). Giving of empathic support is often not just helpful to the one who is receiving but also to the one giving.

It is important for the group as a whole to commit to the development, care and well-being of their fellow members in addition to their own. The social worker must create opportunities for the members to commit to this through the introduction of acceptance between members. This is demonstrated through the support and compassion showed towards members by the worker. These messages need to be shown consistently regardless of good and bad times within the group process (Steinberg, 2004).

*(f) Mutual demand*

Mutual demand calls for members to deal with their concerns. It often requires deep self- reflection and restructuring of thought patterns, working out of issues and finding solutions to problems. This is often a slow and hard process, but the group context can provide the environment in which issues can be properly faced and dealt with (Steinberg, 2004). Mutual demand is achieved when group members are able to put their own feelings and ideas to one side and listen to and support others in the group (Garvin *et al.*, 2004). Although support is vital, it is not sufficient in itself. In order for change to take place there is a need for group members to grow. Mutual demand is also operationalized when members feel that they have undertaken a complicated action (Gitterman & Shulman, 2005). The worker needs to reiterate the fact that old ways of thinking might have to be questioned but that this will be done in an environment that is safe, supportive and understanding (Steinberg, 2004).

*(g) Individual problem solving*

As optimism, wishes and worries of various individuals come together within the group context it is guaranteed that collective problem solving will take place. As these issues are explored in the group, opportunity for members to look at their own experiences are provided, they endeavour to deepen understanding, build compassion and help others in addition to themselves (Steinberg, 2004).

By helping another person solve their issues in caring for the unique needs of their disabled children, other group members are not just allowing for individual problem solving, but they themselves learn how to deal with the same or similar issues (Garvin *et al.*, 2004).

*(h) Rehearsal*

By helping members examine the implications of the way in which they act or react is something group work can achieve quite well (Steinberg, 2004).

Rehearsal as a form of problem solving entails the opportunity for group members to try new behaviour within a safe environment (Garvin *et al.*, 2004). Gitterman & Shulman (2005) explains that sometimes the practicing of a complex task with the support and advice from group members is enough for the receiving group members to actually go and try it in their environment outside the group context.

Members can be assisted in rehearsing when they are encouraged to take beneficial risks. This means that they should take risks with the perception that making mistakes is really desirable as it allows for new ways of doing and for learning to take place. Group members should thus encourage each other to take risks. Group members are also encouraged through suitable activities such as role-play to take advantage of situations in which new ways of thinking and doing is proposed. Rehearsal is best achieved in groups that share mutual ground and is viewed as a community. Members also need to understand that a greater value is placed on trial and error rather than trying nothing at all (Steinberg, 2004).

*(i) Strength in numbers*

Individual caregivers of FASD children often feel overwhelmed by attempting to deal with big institutions and agencies without success. However, by being part of a bigger unit strength is found (Gitterman & Shulman, 2005). This is achieved when problem solving becomes collective and the group shows strength in their numbers. This will allow for members of the group to gain courage (Garvin *et al.*, 2004). Collective power is used to take action on behalf of one group member or the group as a whole. Group members are supported by the fact that they do not have to fight alone and that they are supported by a group of unique individuals all with unique strengths that contribute to their functioning (Steinberg, 2004).

Hyde (2012) investigated the perceived benefits from the views of caregivers who participated in a mutual aid group and found that the most common reason for joining the group was to discover new ways of managing, to reduce their anxiety levels and to share their understandings with other individuals they had something in common with. She concluded by suggesting that mutual aid support groups contribute to the reduction of caregiver problems.

### **3.9.2 The educational approach**

Education is fundamental to social work practice (Sands & Solomon, 2003). Sands and Solomon (2003) further stated that education is fundamental to change. As caregivers of FASD children need to learn more about FASD and how to manage the consequences thereof, participation in such a group will allow for them to do so.

According to Reid (1997) and Yalom (1995) the participation in a group with an educational approach provides the members with opportunity to gain medical or psychological information on issues such as FASD, gain new knowledge on how they are perceived and to develop new interpersonal skills. When an educational approach in group work is initiated the worker must understand and foster the development and mutual aid of the group (Sands & Solomon, 2003). Such groups work on premise that group members may have a lack of knowledge or skills on certain aspects which interferes with their daily functioning (Hatfiels, 1994; Zastrow 2014). Sands and Solomon (2003) continue to explain that education purposes to cultivate long-lasting, planned bodies of understanding and general problem-solving abilities that will help members in current circumstances as well as those that will still occur.

For group work with an educational approach to be successful, the worker needs to have an understanding of what challenges members face and relate new knowledge to that which they already own. Together with this, each group session needs to be carefully planned to ensure that key concepts are covered and that each session fits into a greater whole that follows a consistent and patterned manner. The worker needs to ensure that the giving of new knowledge is not a mere passive activity but that they must have the aim of applying the new knowledge to their life circumstances (Hudgins, Phye, Schau, Thiesen, Ames & Ames, 1983).

Through the group progression support and information is offered by the worker and swapped by the members (Sands & Solomon, 2003). An educational group work approach provides a foundation where individual members with common challenges such as FASD can share their experiences, the ways in which they manage approaches of problem-solving that has worked for them. They can also become part of a support system in which the atmosphere of community is developed. Group members bring first-hand knowledge to the fore and as the knowledge and security between them grow, they will begin to function as co-facilitators together with the group worker. Within the group, members will come to realise that they are not alone and that there are others that share their anxieties and difficulties which in the end brings reason for them to hope in a better future (Sands & Solomon, 2003).

In a study conducted by Brown *et al.* (2005) foster caregivers reported the need for education for the whole family about FASD. They also shared that they had benefitted from advice and information that they have gathered in their support groups, where they built relationships with other foster caregivers. Malbin (2002) described how a paradigm shift had taken place for caregivers of FASD children after receiving education on FASD. These caregivers were able to move their thinking about the child as being “annoying, lazy, fussy, acting younger and inappropriate” to rather think about the child as “frustrated, challenged, tired of failing, being younger and over sensitive”.

According to Jones (1999) there is a noticeable need for educational teaching. Caregivers need training in general but one will notice an increase in the need and desire of caregivers for children with FASD. This education needs to cover the disability in itself as well as general training on how they will have to deal with and rear their affected child. Training increases the skill and knowledge levels of caregivers (Burry, 1999). Bertrand (2009), found that in the interventions programs which he reviewed, success was found in the following: the education of caregivers on FASD and its implications, caregivers needed specific training on parenting strategies and a collaboration with community services were required. Even though educational approaches in group work are helpful it can become patronizing and disempowering if group members are not given the opportunity to share their own experiences and skill (Hyde, 2012).

Even though the educational group work approach can be criticised for having the primary function of being informational, it definitely also includes support aspects and allows for feelings of isolation to be reduced.

The following *objectives* would be typical to a caregiver support group with an educational approach (Sands & Solomon, 2003):

- Increasing group members’ knowledge on the topic and reason for formation of group;
- To foster the expression of outlooks about caregiving;
- To develop abilities in managing with caregiving;
- To provide group members with information on how to access resources within the legal, economic and communal spheres;
- To explore alternatives to caregiving in group members’ own environments;



- Increasing individual members' individual and communal supports;
- For this group to be successful the worker needs to be able to keep with the identified objectives of the group but be able to balance it with flexibility in being able to identify and support individual needs of group members.

Sands and Solomon (2003) have also provided the following aspects regarding an educational group work approach which will be discussed below. The *timeframe* of such group vary from group to group but it is important that it is extended appropriately in order for group members to integrate the new gained knowledge into their own lives and to practice the new acquired skills. Within a longer period of time group members also start to become emotional support networks to each other that can challenge and support each other with the new endeavours each take on.

An educational group work approach has an added value in being able to accommodate speakers from various spheres. The group worker is able to include various guest speakers who are knowledgeable on the topic of Fetal Alcohol Spectrum Disorder. Inputs from medical specialists, lawyers, educational specialists and individuals who have reached success are available. Group members are given the opportunity to tap into the knowledge pool of such individuals to gather information that they need at that time or might need in the future.

Within an educational approach interaction between members can be made *creative* through the use of activities such as role-plays, using media, and collective problem solving. Not only will it support the interaction between members it will also keep them interested and committed in attending as they find it to be enjoyable.

Without understanding FASD non-biological caregivers may internalize the blame they receive from others regarding the way in which the child is reared, it is thus of utmost importance that they receive education about how FASD is caused, what the nature of the disorder is in terms of cognitive-, emotional and behavioural indicators. Caregivers will need information on how FASD exhibits itself in the various developmental stages of the child's life as such information will enable them to foresee changes that children will experience as they grow and to develop expectations that are realistic for the child and themselves (Murthy, Kudler, George & Mathew, 2009). Apart from educating caregivers

on the nature and implications of FASD, the group can provide an opportunity for members to be educated about relevant local services and resources that they can access for the educational, social and medical care of their affected child (Brown & Bednar, 2004).

Brown and Bednar (2005) conducted a study with 63 foster caregivers of FASD children and found that one of the key aspects regarding their views on what is needed to provide adequate care for the child was education about FASD and advice on responsive parenting techniques. Positive outcomes will result for both caregivers and FASD children when the caregivers know how to manage with the differences in rearing methods for affected children.

In order for caregivers of FASD children to optimally care for the child, they need tremendous support of their own. And the most effective way this can be achieved is through education on the topic (Rowbottom *et al.*, 2010). Group members are encouraged to concentrate on using the provided material and the ideas of fellow members in addition to their personal resources to make productive changes in their lives to handle their challenges better (Sands & Solomon, 2003).

An educational approach is important in working with groups that need to gain a better understanding in an environment that is patient, empathetic and controlled but flexible if necessary. Whether education is the primary or subordinate approach of a group, it still is important (Sands & Solomon, 2003) and has helped countless individuals grow to a place where they are better able to cope with their life circumstances.

### **3.10 POSITIVE AND NEGATIVE ASPECTS OF SUPPORT GROUPS**

Within the next section focus will be placed on both positive- and negative aspects that can be experienced in the support group context.

#### **3.10.1 Positive aspects**

##### ***3.10.1.1 Expand understanding on FASD***

Support groups empower members through providing opportunity for new knowledge regarding this disorder to be learnt. Caregivers will be able to understand the limitations and challenges the child

may experience. This new knowledge will also ensure that the caregiver is able to communicate with other role players such as educators, other family members and health care specialists in how to meet the unique needs of the child (Weiner & Morse, 1994).

#### **3.10.1.2 Help caregiver to help the child**

A beneficial strategy is to teach caregivers ways in which they can support their children to reach their full potential. This is attained through the joining the acquisition of new skills together with their perceived strengths and needs of the child (Weiner & Morse, 1994).

#### **3.10.1.3 Acquiring and employing new strategies**

Through the participation in support groups members have the opportunity to build on new strategies that will be beneficial and that they need to continue to seek ones that would suit their unique situation best (Porty, 2009).

#### **3.10.1.4 Sharing experiences**

Group members perceive benefit in groups where they are able to obtain information through listening to the individual experiences of fellow group members. The sharing of experiences enables caregivers to increase support and understand their own situation better (Citron *et al.*, 1999).

#### **3.10.1.5 Finding mutuality**

Group members of a study conducted by Citron *et al.* (1999) shared that meeting others with similar problems and who would not judge them, made it easier to open up during group sessions. Beaton (2005) also found that it was commonly stated that caregivers without FASD would never truly understand what caregivers of FASD children go through daily.

#### **3.10.1.6 Using humour**

Brander and Roman (1999) stated that being able to joke and laugh at oneself in the midst of hardship proves to help the individual maintain emotional stability. It can also be an effective tool used to discover, enable, participate and empower members of the group. Lastly, humour also allows for

individuals who feel vulnerable due to new situations they are facing, to feel ease and relief and so be ready to take on the unknown.

#### **3.10.1.7 Inspiring hope**

In seeing others cope and overcome similar problems, provides significant help by allowing for individuals to trust that they will also get through and that they will have the ability to survive (Lieberman, 1979; Maxmen, 1973). Porty (2009), agreed by sharing that group members in her study found hope in the fact that they would find strength from the group process.

#### **3.10.1.8 Mentorship**

Group members find the input of expert members to be very helpful. Their guidance brought successful strategies to the fore and helped caregivers find new ways in coping with their FASD children. Some members also shared that these experts gave them support outside of the group context, which made a tremendous difference (Porty, 2009).

### **3.10.2 Negative aspects**

The following negative aspects were all results from the research study conducted by Porty (2009).

#### **3.10.2.1 Anticipating future challenges**

As helpful as the sharing of experiences can be, a group member in a study conducted by Citron *et al.* (2009) shared that she was forced to face the difficult future that awaited her when other group members shared their problems. Porty (2009) agreed by saying that group members shared that by hearing the dreadful stories of peers created anxiety for their own futures.

#### **3.10.2.2 Disappointment in group process**

Porty (2009) highlighted that some of her group members shared disappointment in the fact that the group had not met with their expectations and that groups had not met the needs experienced by the caregivers.

### ***3.10.2.3 Poor operational functioning***

Group members shared their frustration in the lack of organisation and lack of structure that the group process had taken on which negatively impacted on their emotional experience (Porty, 2009).

### ***3.10.2.4 One-size-fits all mentality***

Group members became frustrated when they were continuously offered general advice on their unique situation. They were not viewed as an expert who understood their child best; instead group members and the worker were insistent on giving their opinions on what works best in their own situation (Porty, 2009).

### ***3.10.2.5 Friction within the group***

Some of the group members shared that the interaction with other members would often impact on them enjoying the group. Irritation would be experienced when some members showed superiority to the rest of the group as they spoke about their success stories (Porty, 2009).

### ***3.10.2.6 Jealousy over other members***

Some group members shared that they felt it unfair that some members had access to greater resources when they themselves struggled. Even though the fortunate members were able to encourage the rest in how to gain these resources, the practical implications were more complicated (Porty, 2009).

## **3.11 CONCLUSION**

Although some families of children with FASD might not require high levels of intervention, there are undoubtedly many families who would benefit from having ongoing guidance on how to parent these children, particularly as their child navigates their way through increasingly complex developmental challenges (Paley & O'Conner, 2011). As the understanding of FASD increases, more effective interventions for children at home, school and in the community will be developed, and medical, social services, and educational professionals will be better equipped to address the complex problems that face affected children and their families (Weiner & Morse, 1994).

Since the survival of support groups is dependent on their membership perceiving them as beneficial, feedback on successful aspects to achieving the goal of support has a practical application (Citron *et al.*, 1999). Porty (2009) concluded from her study that even though support groups are helpful, they should not be seen as the only option in providing support to caregivers. Other aspects such as policy amendments and education and health services need to be adapted to meet needs of FASD children and their families.

## CHAPTER 4

### EMPERICAL STUDY REGARDING THE UTILISATION OF SUPPORT GROUPS FOR NON-BIOLOGICAL CAREGIVERS OF CHILDREN WITH FASD

#### 4.1 INTRODUCTION

Due to the fact that many non-biological caregivers will be affected by children prenatally exposed to alcohol entering their homes, it is of vital importance that they receive optimal support (O'Malley & Streissguth, 2003). Durand (2007) concluded in his study that non-biological caregivers are incompetently trained to deal with the challenges arising from child placements and that welfare organisations are not adequately resourced to assist them. Within this chapter the researcher will present the voices of the non-biological caregivers of FASD children in a South African context. The primary emphasis will be on the experiences and utilisation of support groups by non-biological caregivers of FASD children. Mahajarine, McHenry, Cheng, Popham and Smith (2013) referred to the importance of educating non-biological caregivers because children with FASD regularly experience challenges as a result of their disability. These challenges may have a negative impact on the caregiving relationship often resulting in unpredictability and numerous placements. Considering this, it is clear that caregivers need a clearer understanding of FASD and how to apply this information in order to improve the outcomes for children within the care system. According to previous studies (Soliday *et al.*, 1994) consulted during the literature review, it was clear that a support group context can provide vital support and much needed information to its members through an educational approach and a mutual aid approach. Whether these approaches are applicable in the South African context of support groups will also be discussed in the following chapter.

## 4.2 DELIMITATION OF THE INVESTIGATION

From working in the social work field, the researcher has gained personal experience and become aware of the fact that caregivers are faced with the challenge of caring for children with FASD without sufficient support to assist them in their unique situations. A literature study was conducted to investigate whether a support group context could provide non-biological caregivers with the necessary support in the absence of other required resources. Two approaches to group work came to the fore as crucial elements to such a group, namely *mutual aid education*. Each of these approaches to groups were analysed and important elements of each discussed. The majority of literature available to the researcher was of an international nature and the researcher wanted to understand these approaches in a South African context.

Both *quantitative* and *qualitative* research was utilised in order to gain a clearer understanding of non-biological caregiver experiences surrounding the utilisation of the support provided to them, in order to provide the FASD children with a caring and stable environment in which to grow. The aim was to gain an in-depth understanding of the phenomena from the participants' point of view (De Vos *et al.*, 2011).

The initial *sample* consisted of 20 participants but the final sample of this study consisted of 16 non-biological caregivers of children with FASD, who have been part of a support programme in the Western Cape specifically dealing with this disability. The researcher did not deem it necessary to interview more participants as the study had reached saturation and sufficient data had been collected that provided the researcher with a thick description of the experiences of non-biological caregivers of FASD children. Reaching a level of saturation was used as guiding principle when the researcher found that the collected data became repetitive (Mason, 2010).

## 4.3 GATHERING AND ANALYSING DATA

The researcher was provided with the names and contact details of caregivers of FASD children who were referred to an organisation by other welfare organisations or who had approached the organisation for help themselves. See annexure E for permission to do the research in the



organisation. The non-biological caregivers who had attended at least 5 group sessions were identified and contacted telephonically after which an interview time and location was scheduled with the participants. *Semi-structured, one-on-one interviews* (De Vos *et al.*, 2011) were conducted with one representing caregiver per household in order to gather information about the experiences and utilisation of support groups. This method allowed the participants to share their personal experiences and beliefs in a rich and detailed manner (De Vos *et al.*, 2011). A *pilot study* was conducted using two participants who qualified for inclusion in order to ensure that no questions were ambiguous or limiting to the study (De Vos *et al.*, 2011). The outcome was that some of the questions were difficult to understand and the researcher then made necessary changes to her interview schedule. All interviews were conducted in July-August 2014 in either Afrikaans or English and were recorded with permission from the participants. The researcher explained that complete confidentiality would be maintained and consent forms were explained and then signed by both parties. Participants were encouraged to ask for a better explanation if any of the questions were unclear. The interviews generally lasted about 45 minutes each. The audio recordings were transcribed shortly after the interviews took place. This chapter will compare the gathered data to the literature study and new truly South African contextual data will also be provided.

The transcribed data will be presented schematically and identified themes, sub-themes and categories will be presented in tables throughout this chapter. Narratives that best voiced the experiences of participants and reflects the captured essence of the themes were chosen and are provided in this chapter as well.

The study had a broad focus on the utilisation and experiences of support groups as voiced by participants of this study, thus a primary focus is not placed on general identifying details such as educational status, age, gender, income and social stratification. There is also not an in-depth focus on theoretical underpinnings of group work in this chapter as it was less important for the purposes of this study.

**Table 4.1 Schematic representation of Empirical Study**

Themes	Sub-themes	Categories
1. Identifying details	1.1 Residential area of non-biological caregiver	
	1.2 The time period in which the non-biological caregiver has cared for children affected by FASD	
	1.3 Caregiving relationship to children	
2. Implications of FASD on children	2.1 Knowledge of FASD before an affected child enters placement	
	2.2 Reactions to when finding our child is affected	
3. The extent to which non-biological caregivers are affected by the consequences of FASD	3.1 Areas of challenge	<ul style="list-style-type: none"> <li>• Gaining educational environment for children</li> <li>• Keeping the children involved in society</li> <li>• Adapting household to meet the unique needs of FASD children</li> <li>• Dealing with new and continuous behavioural problems</li> <li>• Sexual urges of FASD children</li> <li>• Sudden aggression outbursts</li> </ul>
	3.2 Implications due to FASD	<ul style="list-style-type: none"> <li>• Emotional conflict</li> <li>• Continuous setbacks</li> <li>• High levels of stress</li> <li>• Exhaustion</li> <li>• Being able to care for self</li> <li>• Having access to respite care</li> <li>• Battling for support</li> <li>• Thinking about the possibility of forever parenting</li> <li>• Feel unappreciated and taken for granted</li> <li>• Being able to make and keep plans</li> <li>• Experiencing loss and grief in thinking about the children's future</li> <li>• Experiencing fear and hopelessness for the future of child</li> </ul>

		<ul style="list-style-type: none"> <li>• Feel judged by others</li> </ul>
	3.3 Being able to access services to assist non- biological caregivers in caring for the FASD children	<ul style="list-style-type: none"> <li>• Medical assistance</li> <li>• Services rendered by Non-Governmental Organisations</li> <li>• Religious Institutions</li> <li>• Special education</li> </ul>
	3.4 Social worker's understanding of FASD and the ability to render services to support non-biological caregivers	<ul style="list-style-type: none"> <li>• A lack of understanding FASD</li> <li>• Lack of contact and follow up</li> <li>• Turnover of staff</li> <li>• Struggling for grant</li> </ul>
	3.5 Other children and family members in the household being affected	<ul style="list-style-type: none"> <li>• Other children in the household</li> <li>• Other family members</li> </ul>
	3.6 The understanding of FASD by extended family members and friends and their ability to support non-biological caregivers	
4. The utilisation and experiences of a support group	4.1 The need for support in caring for children affected by FASD	
	4.2 Support groups playing a vital role in supporting non-biological caregivers	<ul style="list-style-type: none"> <li>• Provision of emotional and educational support</li> <li>• Understanding the child better</li> <li>• Ineffective support groups</li> </ul>
	4.3 Amount of sessions attended	
	4.4 Ways in which support groups help non biological caregivers cope better	
	4.5 Meeting the group member's expectations about the group sessions	
	4.6 Emotional support in the support group context	<ul style="list-style-type: none"> <li>• Absolute respect and non-judgmentalism by group peers</li> <li>• Common/ shared/ reciprocal relations to other non-biological caregivers</li> <li>• Normalisation of circumstances/ situation</li> </ul>

		<ul style="list-style-type: none"> <li>• Encouragement of significant emotional progress</li> </ul>
	4.7 Practical support in the support group context	<ul style="list-style-type: none"> <li>• Enabled to change thought patterns regarding FASD</li> <li>• An opportunity for respite/ rest</li> <li>• Linking with resources within the group</li> <li>• Enabled to advocate within the group context</li> <li>• Innovation/ improvement and training between group members</li> <li>• Receiving practical tools</li> </ul>
	4.8 Approaches in support groups: mutual aid approach and educational approach	<ul style="list-style-type: none"> <li>• Assisting caregivers to utilise their own strengths</li> <li>• Feeling like part of a community within the support group</li> <li>• Teaching the purposeful use of self</li> <li>• Participants feeling like they had something worthwhile to offer the group</li> <li>• Being able to talk and listen to fellow group members</li> <li>• Discussing Taboos and forbidden topics within the group</li> <li>• Feeling like others are “in the same boat as you”</li> <li>• The support group as a helper in facing difficult situations and coming up with new viewpoints and strategies</li> <li>• Being able to problem solve better as an individual</li> <li>• Role play taking place</li> <li>• Gaining better insight and understanding of FASD after attending a support group</li> <li>• Being provided with relevant information that could applied in caring for affected</li> </ul>
	4.9 Positive aspects within a support group	<ul style="list-style-type: none"> <li>• Increased understanding of FASD</li> <li>• Helping to care better for FASD children</li> <li>• Gaining and employing of new strategies</li> <li>• Sharing experiences</li> <li>• Finding mutuality</li> <li>• Using humour</li> <li>• Inspiration to hope</li> </ul>

		<ul style="list-style-type: none"> <li>• Mentorship relationships</li> <li>• Praying together</li> <li>• Friendship</li> </ul>
	4.10 Negative aspects within a support group	<ul style="list-style-type: none"> <li>• One-size-fits all mentality of group members</li> <li>• Disappointment in the group process</li> <li>• Anticipation of future challenges</li> <li>• Friction between group members</li> <li>• Jealousy over the well-being of other group members</li> </ul>
	4.11 Recommendations or changes for support groups suggested by non-biological caregivers	<ul style="list-style-type: none"> <li>• Suggestions that support group should include information about HIV/ Aids</li> <li>• Assistance in dealing with teenage pregnancy and the prevention thereof</li> <li>• Support groups need to be more accessible in communities</li> <li>• Having a purely emotional support group context</li> <li>• Getting together again later</li> </ul>

## 4.4 RESULTS OF INVESTIGATION

Findings of the study will be discussed under the following themes:

**Theme 1:** Identifying details

**Theme 2:** Implications of FASD on children

**Theme 3:** Extent to which non-biological caregivers are affected by the consequences of FASD

**Theme 4:** The utilisation and experiences of support groups

### 4.4.1 Identifying details (*Theme 1*)

#### 4.4.1.1 *Residential area of non-biological caregivers (Sub-theme 1.1)*

Participants were asked to indicate where they currently reside. Half of the participants (50%) reside in an informal settlement and the other half (50%) reside in a town, both in the Milnerton Suburbs. From this data it is clear that non-biological caregivers from all geographical areas can be affected by FASD and not just previously disadvantaged areas.

#### 4.4.1.2 *The time period in which the non-biological caregivers have cared for children affected by FASD (Sub-theme 1.2)*

The numbers of children in care who are affected by FASD as well as how long participants have been caring for the specified children are indicated in Table 4.2.

**Table 4.2 Time period of non-biological caregiving role to FASD children**

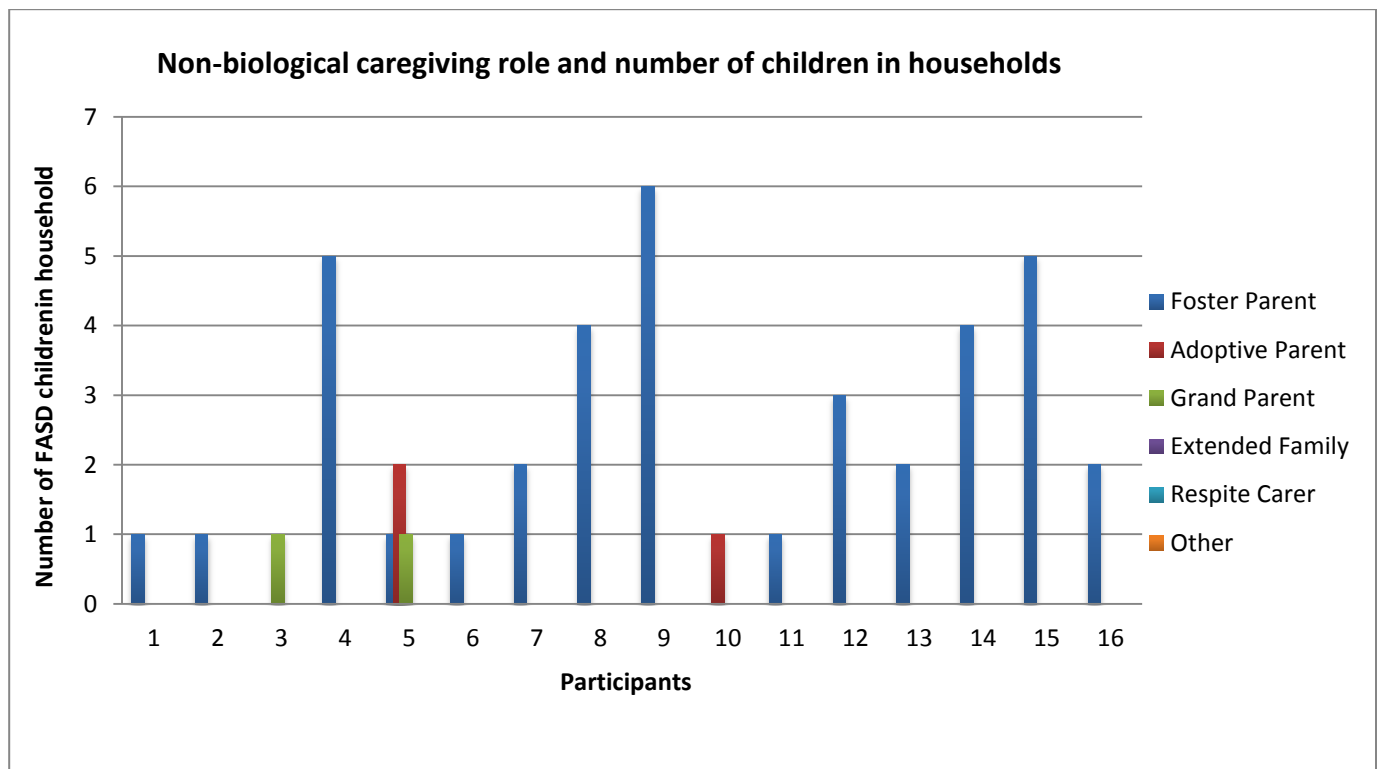
Number of children in household affected by FASD	Period of time in non-biological relationship with FASD children
1	14 years
4	12 years
2	12 years
5	10 years
1	11 years
2	10 years
1	10 years
6	8 years
1	8 years
1	8 years
3	7 years
5	5 years
4	4 years
1	4 years
2	2 years
1	1 year

**N=16**

As seen in the above table, 69% of the caregivers have been caring for non-biological children for more than 5 years and have reported that they do receive some form of support to help them care for their children. The remaining 31% have been caring for their children for less than five years. The shortest period of time is one year.

#### **4.4.1.3 Caregiving relationship to children (Sub-theme 1.3)**

Participants were asked to indicate what type of non-biological caregiver role they fulfilled with regards to the amount of children in their care. The findings are shown in Figure 4.1 below.



**N=16**

**Figure 4.1 Presentation of caregiving role to children**

As seen above 14 (87,5%) of the participants indicated that they were foster caregivers, two participants (12,5%) indicated that they had adopted the concerned children and two participants (12,5%) indicated that they were a grandparent. These results are consistent with the findings of Swanepoel (2009) indicating that the needs for foster care placements are the highest among all types of alternative care. Children who enter out-of-home placements are most likely to be placed in a foster home and this is no different for children affected by alcohol (Brown *et al.*, 2004).

Also indicated by the above figure 4.1 is that 6 of the participants (37,5%) reported that they had one child in their care affected by FASD; 4 participants (25%) reported two to three affected children in their care; 3 participants (19%) reported four affected children in their care; and 3 of the caregivers (19%) reported that they had between five and six children in their care. This is consistent with the findings of De Beer, Kritzinge and Zsilavec (2010) that children with FASD are often placed in foster care due to unfortunate social conditions.



#### **4.4.2 Implications of FASD on children (*Theme 2*)**

##### **4.4.2.1 *Knowledge of FASD before affected children enter placements (Sub-theme 2.1)***

The participants were asked if they had any knowledge regarding Fetal Alcohol Spectrum Disorder before entering into a caregiving relationship with their affected child or children.

All the participants (100%) indicated that they had not heard of FASD before an affected child had been placed in their care. This correlates with the findings of Kellerman (2010). She investigated the readiness of the child protection systems in Arizona to address the reality of FASD and found that although FASD is the most common social problem in Arizona, it is also the least recognised in their welfare service system. She continues to state that FASD is possibly the biggest health and social issue that society is facing, yet it goes unrecognised. Although these findings are of an international nature, the South African context shows a similar trend. Rendall-Mkosi *et al.* (2008) completed a Situational and Gap Analysis and concluded that there is limited awareness amongst professionals and lay people about FASD. This in turn, makes assessment of needs and service provision for FASD affected individuals increasingly difficult. Rutman and Van Bibber (2010) agreed by stating that there is a general ignorance about the nature and consequences of FASD, and the lack of day-to-day support available to those in need thereof.

##### **4.4.2.2 *Reactions to when finding out the children are affected by FASD (Sub-theme 2.2)***

Participants were given a list of possible reactions they may have experienced when finding out that the concerned child or children were affected by prenatal alcohol exposure. They were also given the opportunity to add any reactions that were not provided on the list. The results are shown in Table 4.3.

**Table 4.3 Possible reactions to finding out the children are affected by FASD**

Reactions	Total participants
Helplessness	6 (37,5%)
Anger	5 (31%)
Anxiety	4 (25%)
Denial	4 (25%)
Frustration	3 (19%)
New opportunity	3 (19%)
Grief	2 (12,5%)
No emotional reaction	2 (12,5%)
Fear	1 (6%)
Pity	1 (6%)
Horrorified	1 (6%)
Disappointed	1 (6%)
Bad	1 (6%)

**N=16**

Feeling helpless was the most common reaction. A feeling of anger was the second most experienced reaction with five (31%) of the participants showing anger specifically towards the biological caregivers of the affected children. It can be seen in the three narratives below:

-“*Ek was **kwaad met haar ma...***”  
*[I was **cross with her mother...**]*

-“*They are such saints they have done nothing. How can they suffer from their mothers’ sins because it is not them who wanted to be like that? **It is their families who made them like that.***”

-“*... **Horrorified that moms could do that to their children.***”

Four (25%) participants experienced anxiety and denial and a further three participants felt frustration. Three participants (19%) viewed their circumstances as a new opportunity. This can be seen in the following quote from a carer who had adopted a diagnosed FAS child.

-“*Um ok, no-no-no. **I’m a positive person**, so it gave me the **opportunity to research** it and find out more about it...*”

Two (12,5%) participants experienced grief and two (12,5%) felt no emotional reaction towards finding out. Feelings of fearfulness, pity, disappointment, being horrorified and feeling bad for the child was experienced by one (6%) participant.

From the above mentioned findings it is evident that non-biological caregivers can experience various reactions to finding out ranging from anxiety and denial to viewing it as a new opportunity.

#### 4.4.3 The extent to which non-biological caregivers are affected by the consequences of FASD (*Theme 3*)

##### 4.4.3.1 Areas of challenge (*Sub-theme 3.1*)

Caregivers were asked if they had faced challenges in the following four areas; gaining an educational environment for child and or children, keeping the child and or children involved in society, adapting your household to meet the unique needs of FASD children and dealing with new and continuous behavioural problems. They were also given the opportunity to add any challenges not mentioned by the researcher. These findings are shown in Table 4.4.

**Table 4.4 Challenges faced by non-biological caregivers**

Areas of challenge	Yes	No
Dealing with new and continuous behavioural problems	16 (100%)	0 (0%)
Gaining educational environment for children	12 (75%)	4 (25%)
Keeping the children involved in society	10 (62,5%)	6 (37,5%)
Adapting household to meet the unique needs of FASD children	6 (37,5%)	10 (62,5%)
*Other:		
Sexual urges of FASD children	1 (6%)	0
Sudden aggression outbursts	1 (6%)	0

**N= 16**

The areas of challenge will now be discussed.

*Dealing with new and continuous behavioural problems:* All of the participants (100%) experienced behavioural problems. One foster mother explained the following about how differently her children behave:

*-“Uhm dealing with new and continuous behaviour problems because you dunno exactly what is coming out of them, you dunno what, each one’s individual. Some is individual to X, he is individual to both of them, for instance Y, he’s quiet and calm, he has his blow ups, X is. Sy kop hak uit, Z he’s got a behaviour problem that is for certain. X is he can be cheeky, obstructive, W*

*is on his own, that's what I find. He's always on his own, he can in the mornings be **grumpy** and things but he's fine, but X he's another "**kettle of fish!**" [Laughs]."*

Porty (2008) came to the same conclusion by stating that caregivers were stressed by dealing with extreme, irrational and unforeseen behavioural challenges. There was common agreement that caring for an FASD child was unlike any other caregiving role previously experienced.

Gaining an educational environment conducive to the needs of children with an FASD can be a challenging task as seen by the response of 12 (75%) of the participants. Some of the responses were as follows:

*- "Nee, hulle het net **gesê sy is 'un-teachable'**; sy kan nie geleer word nie daar is 'n problem." [No, they just **said that she is un-teachable**, she can't be taught, there is a problem].*

*- "She always come home and says they've been beating me... **they do not understand**... so, it's not that I'm the mind the schools from the township... but I think I've seen... I think I prefer the... I prefer the private schools. The schools that are gonna help them."*

*- "The most thing that is troubling me is that the **disable girl is not getting education she is been sitting here at home for the past two years**. She is 17 turning 18 in October and she needs some kind of help. A school for skills."*

According to Kodituwakku, May, Clericuzio and Weers (2001) the majority of children with prenatal alcohol exposure fall within a mild category of disability and will thus remain in the mainstream education system of South Africa, which is poorly resourced to provide adequate support for their disabling developmental, attention and executive functioning difficulties.

Keeping the children involved in society was found to be a challenge by 10 (62%) of the participants. Caregivers often found it difficult to keep their children involved with peers due to poor social skills their affected children present with (Brown & Bednar, 2008). A total of 6 (38%) participants said that they had no problems and that their children were able to socialise within the community. A study conducted by Clark, Minnes, Lutke and Ouellette-Kuntz (2008) correlates by stating that caregivers of FASD children managed to attain a level of community integration for their children through the continued efforts of outside support and family.

Adapting your household to meet the unique needs of FASD children was not a problem for most of the caregivers with 10 (62,5%) participants reporting 'no'. This was interesting as one key problem for

most FASD caregivers has been to consistently change and restructure the environment of the child for positive outcomes (Weiner & Morse, 1994). The responses of participants could be resulting from the support group they attended that has assisted them in adapting their household as seen in this narrative:

*-“Ja, dit het my baie gehelp.... toe ek nou by die support group kom toe hoor ek niks baie prente nie, niks prente eintlik nie, die gordyne is bruin of vaal of die colour wat die mure moet baie lig wees, en niks baie goed op hulle kaste nie en dit moenie ge-oorclutter wees nie so ek het al daai goeters verwyder en um, en is om vir hulle meer kalm te hou en meer vir hulle te kalmeer, want ek het al gesien hulle raak verskriklik.”*

*[Yes, it has helped me a lot... when I got to the support group I heard, that I’m not allowed to put up a lot of pictures, actually nothing, the curtains must be brown or pale or the colour of the wall must be very light, not a lot of things on their cupboards and it mustn’t be over-cluttered so I removed all of those things and um, it is to keep them calmer and to calm them because I have seen they can become terrible].*

It could also be due to the fact that they did not have over-cluttered and big homes to start off with as stated by one participant;

*-“No, since it is a small house...”*

Caregivers were given the opportunity to mention any additional challenges they may have experienced. A participant mentioned that she was struggling with inappropriate sexual behaviour shown by some of her older children:

*-“A child just like for instance like calling out my name and ‘please come have sex with me’ and that and I even heard that and things like that, I do not feel very comfortable talking to outside people about those things.”*

Sudden outbursts of aggression were also reported as an additional challenge by the above-mentioned participant who described it in the following manner:

*-“I face uhm, especially when it comes to the sudden outbursts and then they just like, like they want to attack you or something like that and I would just stand back and say eish, then I have to really think what do I do? How do I handle this?”*

Linking with the above narrative are the findings of the Foundation for Alcohol Research and Education (2010) which shared the experiences of carers who highlighted the difficulty experienced in managing severe and ‘unbelievable meltdowns’ of their children, which sometimes even resulted in

injury. Whitehurst (2011) also mentions this issue and explains that as children develop new behavioural problems will arise. FASD typically displays itself in subtle behavioural signs but develops into more noticeable and regular symptoms as the child ages.

#### **4.4.3.2 Implications due to FASD (Sub-theme 3.2)**

The participating caregivers were asked if they experienced some of the following implications and were able to add any other implications and additional comments if they so desired. The results of the implications experienced are summarised below in Table 4.5.

**Table 4.5 Implications experienced by non-biological caregivers as a result of caring for FASD children**

<b>Implications experienced</b>	<b>Yes</b>	<b>No</b>
Being able to care for self	15 (94%)	1 (6%)
Emotional conflict	14 (87,5%)	2 (12,5%)
Being able to make and keep plans	14 (87,5%)	2 (12,5%)
Having access to respite care	13 (81%)	3 (19%)
Continuous setbacks	12 (75%)	4 (25%)
High levels of stress	12 (75%)	4 (25%)
Thinking about the possibility of forever parenting	12 (75%)	4 (25%)
Experiencing fear and hopelessness for the future of the children?	11 (69%)	5 (31%)
Exhaustion	11 (69%)	5 (31%)
Feeling judged by others?	11 (69%)	5 (31%)
Experiencing loss/grief with regards to the children's future?	9 (56%)	7 (44%)
Battling for support	8 (50%)	8 (50%)
Feeling unappreciated or taken for granted	8 (50%)	8 (50%)

**N=16**

Exhaustion is prevented (Beaton, 2005) by caregivers being able to care for themselves. The majority of participants (94%) in this study stated that they are able to care for themselves. This was an unanticipated finding as previous studies conducted by Figley (1995) found that caregivers are generally too busy caring for the affected child that they are unable to care for themselves. FARE (2012) reported that participants of their study mostly neglected their own health and well-being, believing it to be less of a priority compared to the well-being of the affected child.

Emotional conflict was experienced by 14 (87,5%) of the participants. Brown and Bednar (2008) described the on-going 'battle' that caregivers face and that the experience of anxiety and fear becomes a constant in their lives as they are faced with the child's disability. The challenges are evident in the following narrative where a foster mother shares her experience before joining a support group:

*- "...Before I started with X (support group) I was an emotional wreck. I cried for everything."*

Being able to make and keep plans is often a challenge for caregivers due to the fact that they do not have access to child-minders who are able to look after their children while they visit friends or go out. Together with that, unpredictable behaviour adds to the difficulty of making plans for themselves and the children (Brown & Bednar, 2008). The majority of participants (87,5%) of this study said that they are able to make and keep plans.

Having access to respite care is also a buffer (Brown & Bednar, 2004) against exhaustion as it allows caregivers to take time off from their caregiving responsibilities. According to Rowbottom *et al.* (2010), respite is a necessary but an under-utilised service. Caregivers in this study found it difficult to find individuals competent enough to care for their uniquely challenged children. One participant shared her experience of respite care:

*- "I try to be **selective** with H. I try to find um caregivers or an environment where they understand H and then ja... **it's very seldom you know that I that I do it.**"*

Although respite care is mostly regarded as a professional service, the majority of participants (81%) in this study were able to take a break as a result of close friends or family standing in for them. Three participants working in a Cluster Foster Care Scheme had access to respite workers and were able to take time off every second weekend to rest.

The majority of participants (75%) experience continuous setbacks by constantly having to remind children of tasks and repeating otherwise ordinary activities on a continual basis. Rowbottom *et al.* (2010) identified the same findings of a study she conducted with foster caregivers. The participants reported the need to repeatedly remind their children of habits, schedules and tasks that needed to be followed, in order to compensate for their children's' intellectual challenges. Due to the fact that

FASD children will vary in behaviour from one day to the next (Porty, 2009), it is extremely difficult for them to anticipate behaviour and prevent setbacks. The frustration of having to reteach their children was experienced even by the most knowledgeable and skilled caregivers (Brown & Bednar, 2008; FARE, 2012).

There were 12 (75%) participants who stated that they experienced high levels of stress and another 12 (75%) participants thought about the possibility of forever parenting their children.

Fear and hopelessness was also experienced by 11 (69%) of the participants. One participant explained the following:

*-“Uhm you would think about it, sometimes **you think where would they go what’s gonna happen to them.**”*

The uncertain future of an FASD child who might not be able to live an independent and wholesome life is generally a big concern for caregivers who might not always be there to care for the child (Mukherjee, McHenry, Cheng, Popham and Smith, 2013).

Exhaustion was experienced by 11 (69%) which links to FARE (2012) who stated that caregivers are often exhausted due to the fact that they are faced with the endless and continuous care needs of their children.

In addition to feelings of fear, loss and grief, some caregivers also reported that they feel judged by others. A total of 11 (69%) participants stated that they constantly felt judged by others who didn’t understand their unique circumstances. Participants shared stories of others not understanding their situation and the magnitude of the FASD related trials they face daily. Mukherjee *et al.* (2013) concurs by explaining that caregivers often feel blamed and misconstrued by onlookers and are accused for poor child-rearing.

Thinking about the future of a child is often a hopeful and positive experience but the reality for caregivers of an FASD child is often the opposite Burton *et al.* (2008). Nine participants (56%) shared that they did indeed experience a loss and grief in thinking about the future awaiting their children.



Caregivers find it overwhelming that their dream for their child may never be realised as a result of their disability (Porty, 2008).

Battling for support is a common phenomenon experienced by eight (50%) of the participants. Whitehurst (2011) stated that caregivers constantly spoke about the 'battle' they face in gaining support and even though foster children spend more time with them than with any other representatives in the welfare system, they are the ones least equipped and least supported in their role as caregivers of prenatally alcohol-exposed children (Marcellus, 2010). Participants shared some of the following narratives regarding finding support:

*-“I had to **look for that myself so it’s not a given thing**, you have to research it and look for it and things like that ja.”*

*-“**People do not understand** that you do not... **There are not enough services out there no**. It’s something they just do not understand. **They do not understand...**”*

A total of eight (50%) of the caregivers felt unappreciated and taken for granted on a continuous basis. This is pre-empted by the fact that FASD sufferers often lack the ability to comprehend how their behaviour affects their caregivers who often internalise hurtful statements or actions that cause deep lying hurt (Porty, 2009).

A contradicting finding was explained by one of the carers reporting that she did not feel taken for granted because her FASD affected child always notices changes in or about her and he will be the first to give her compliments. She spoke of the child’s protection and love towards her in the narrative below:

*-“I’m **gonna say no**, and I say no because I think X, out of even my own two, he’ll always say you look nice today, you smell nice today. He notices immediately if my hair’s been highlighted or cut. So, um I’m like his... ja, he... **He’ll fight to the death if it comes to me.**”*

Another comment was made by the same participant on the uniqueness of the children and how they could turn any ordinary situation into an extraordinary situation:

*-“**Nothing about a child I think with FAS I think is just ordinary**. They always just... I dunno, they have this way of turning a pretty mundane ordinary trip to go fishing into something **extraordinarily...**”*

FARE (2012) agrees with the above statements by caregivers that their children had positive attributes as well and that caring for them could also result in joyful and unique experiences. Caregivers noted their children were extremely loving and caring.

#### **4.4.3.3 Being able to access services to assist caregivers with caring for the FASD children (Sub-theme 3.3)**

<b>Sub-theme 3.3</b>
Being able to access services to assist with caring for the FASD children
<b>Categories</b> <ul style="list-style-type: none"> <li>• Medical assistance</li> <li>• Services rendered by Non-Governmental Organisations</li> <li>• Religious Institutions</li> <li>• Special education</li> </ul>

Participants were asked whether they were aware of and able to access support services to assist them with their children. Four categories could be identified. These categories include medical assistance, services rendered by non-governmental organisations, religious institutions and special education and will be discussed below.

Medical assistance was highlighted as important and a number of participants mentioned that their children were on Ritalin because of their hyperactive behaviour and their inability to concentrate at school. Participants also mentioned that some of their affected children were on medication for HIV/Aids. In the narrative below one participant expressed gratitude towards a certain medical practitioner at his local clinic who referred him to a NGO that would be able to assist him by linking him with a school to gain an adequate educational environment for his foster child:

*-“My mind slat vi my mos man **Brooklyn clinic** en daar kom ek by die jong dametjie sy’s vi kinders en sy’t my ingelig. Sy’t my gesê: I’m gonna give you a letter but first I’m gonna phone X to see if you know ... so en vir haar is ek baie dankbaar.”*

*[My mind told me man what about **Brooklyn clinic** and there I got to a young lady who are there for children and she informed me. She said: that she would give me a letter but first she was going to phone X to see you know... so en for her I am very grateful].*

Participants who were able to gain access to specialised services rendered by Non-Governmental Organisations that could help them care for their affected children explained that it helped a great deal. The participants spoke about social workers and professionals who understood their children for the first time and how they were assisted in locating a new school. Also, that there was an available social worker who could come to their home and assist them in managing the home environment. The participants spoke about this being very helpful as seen in the narrative below:

*-“Dis waar ek uitgevind het, **by X het uitgevind wat alcohol sindroom regtig is**, ek het nie regtig geweet wat dit was nie ek’t maar net gedink dis net omdat die ma drink tydens swangerskap...”*  
*[That is where I found out, **From X I found out what FAS really is**, I didn’t really know what it was I just knew that it was because the mother drank during pregnancy]*

*-“Social support what I’m talking about is **if there is any problem or I need advice you’d go to the social worker, the social worker would give you advice if there’s a problem with a child she’d tell you how to handle that child..**”* (Participant speaking about services from a social worker at a local NGO working in the field of FASD).

There was a general agreement amongst participants that religious institutions play an important role in supporting caregivers as described in the following narrative:

*-“**Ondersteuning en so aan en van ons kerk.** Daar is ook baie ondersteuning met iemand wat met haar sal ‘counselling’ doen oor toe sy ‘gerape’ was op die ouderdom van 12 maande en so. En ook, hulle betrek haar altyd by alles.”*  
*[**Support I get from our church.** There is also a lot of support with someone that does counselling with her about when she was raped at the age of 12 months and so. And also, they include her in everything].*

Soliday *et al.* (1994) reported the same finding in his study by showing that foster caregivers shared that their churches were an important support resource.

The children from 10 (63%) of the participants were able to attend special education centres. An individualized learning centre in the local community reportedly provided special education tailored to cater for the unique needs of the children affected by FASD and other neuro-developmental disabilities. It was evident that the caregivers experienced a sense of relief and that they could clearly see a difference, in the well-being and development of their children compared to when they were placed in a public school. This can be seen in the following narrative:

-“Uh um, because he’s with like children and they’ve kind of gone **through all their teething stages together** and there’s been **somebody to guide them and look at them individually** and **not in a whole class environment which was happening here at X where he was kind of singled out as the troublemaker, as the weak one**. But they all together and um ja, he’s motivated to go to school, he doesn’t want to miss school. I’ve seen now in the morning he’s actually going over his work himself, which is something he wasn’t doing before.”

Furthermore, a caregiver shared her opinion on providing a child with an educational environment where teachers are able to address the unique needs of the children and how big of an impact it can have, not just on the child but also on them as caregivers, who no longer have to worry about the schools and educational facilities not being able to manage the children:

-“Um weet jy wat ek dink as dit miskien nie **vir X gewees het wat al die facilities het nie**, dan sou ek gesukkel het om opvoedkundige plekke te kry **want dan moes hulle nou uitgaan by die normale um instansies wat die kinders soos crèche en skole dan sou hulle nie cope nie**.”

[Um do you know that **if it was not for X who has all of the facilities**, then I would have struggled to find an educational place because then they **would have had to go to normal um institutions like crèche and school and would not cope**].

#### 4.4.3.4 **Social worker’s understanding of FASD and the ability to render services to support non-biological caregivers (Sub-theme 3.4)**

<b>Sub-theme 3.4</b>
Social worker’s understanding of FASD and the ability to render services to support non-biological caregivers
<b>Categories</b> <ul style="list-style-type: none"> <li>• A lack of understanding FASD</li> <li>• Lack of contact and follow-up</li> <li>• Turnover of staff</li> <li>• Struggling for grants</li> </ul>

Research shows that foster care placements were profoundly influenced by the level of trust, the nature of received support and an understanding of the relationship between the caregivers and social workers (Mahajarine *et al.*, 2013). The researcher of this study wanted to determine whether the participants felt that social workers were able to assist them in their role as non-biological caregivers and four different categories came to the fore. These categories include: a lack of understanding FASD, lack of contact and follow up, turnover of staff and struggling to secure a grant. They are discussed below.

There was overall agreement amongst participants that the social workers who placed the children in their care had a lack of understanding and could not assist them in any way. This suggests that these professionals need training with regards to implications of FASD. The following narratives were shared regarding this:

*-“I do not believe that the social workers actually understand the effect of FASD on children and I do not believe they are able to... well they haven’t really been able to give me any services. I’ve actually provided my own.”*

*-“He didn’t understand X’s condition, through no fault of his but I think he... I do not know. I do not know if he knows about FAS or how it works...”*

*-“Wat ek dink hulle probeer of hulle weet die ouers het baie gedrink maar miskien is dit nog nie by hulle so uh, ‘n ding om te dink die kinders is veel different of whatever nie, hulle moet **miskien ook nou eers kursusse doen**. So ek dink daar is seker baie werk om te doen in die social workers as ek nou so mooi dink daaraan. **Hulle moet ook opgelei word.**”*

*[What I think they know is that the caregivers drank a lot but maybe it is not such an uh, a thing yet to think that the children are much different or whatever, **maybe they need to first do courses**. So I think that there is probably a lot of work to be done in the social workers if I think about it carefully now. **They also need to be trained**].*

A participating carer also mentioned that social workers need to be well aware of the prospective caregivers’ personality types and have confidence in these caregivers’ ability to care for prenatally alcohol-exposed children.

*-“Hulle behoort om die kinders wat challenges het by... hulle kan **hom nie by enige ouer sit nie verstaan jy, hulle moet ook dan die ouers ken**. Dit is ‘n groot challenge dit wat hulle die kinders plaas is, hulle is nie opgewasse om met die kinders te sukkel nie...”*

*[The children that have challenges... **they can’t just place him with any caregivers understand, they must also then know the caregivers**. It is a big challenge of placing children; they aren’t able to struggle with the children...]*

A study conducted by Brown *et al.* (2005) similarly showed that the appropriate caregiver characteristics and abilities were essential in maintaining a successful and lasting placement. Some of these key characteristics include, being a composed and confident parent who is able to deal with the unique challenges they will face.

A second frustration mentioned was that caregivers have very little faith in their working relationships with social workers saying that they never had contact with- or had received services from the social workers after placement took place.

***-“Niemand bel jou om te hoor is die kind oraat, is jy nog oraat en so nie. So ek voel net daai kant is bietjie swak ingelig met die kinders sê omstandighede.”***

***[No one phones you to hear if the child is alright or if you are alright. So I just feel that that side is ill informed about the children’s circumstances].***

***-“Well I’ve never dealt with them yet, really, and the social worker that placed him with me didn’t check once if he was okay, she vanished from the face of the earth. I could have done with this child whatever I wanted nobody cared, ya.”***

***-“I end up going to the media and it was a big deal because everything was on the papers and I was complaining about the same situations. And we end up fighting with the Social workers. They say why did you expose us, why didn’t you speak with us? I say I’ve been begging and begging.”***

This finding is in agreement with Durand (2007) who found that social work professionals who participated in his study stated that their high caseloads and limited time hindered their ability to give the necessary attention to foster placement follow ups. Crisis management and under developed community resources were also seen as limiting factors. The frequency of follow ups took place from anywhere between once every six months, to once every two years. Considering the challenges that caregivers experience when caring for a FASD child, surely they require support on a more frequent basis.

In addition to the lack of contact, caregivers also shared their frustration of having to deal with many different social workers due to the high staff turnover as seen below:

***-“When I contact the Social worker, they say she’s not a social worker anymore. And then I say please help, because this child drives me mad. She is doing something strange. Uh, and you know, when they replaced the child to me... you know that the mother was an alcoholic, was a drug addict. So, is there any chance you can help me? And the one who took over when the other one eh resigned... and they say no we can’t help you.”***

***-“Ok, firstly we’ve had about nine social workers.”***

Establishing a working relationship with a social worker takes time and commitment but the general perception of the participants was that they were unsuccessful at establishing a relationship, as they hardly dealt with the same social worker. Implications of this would be that no long term trusting relationships can be built with professionals which could affect caregivers and their children negatively.

The struggle to secure financial assistance in the form of a social grant was also a major concern especially for those participants residing in informal settlements. Considering that they were already living with access to limited resources, taking children in would place additional strain on them financially. Participants said that receiving a grant would not be the determining factor for taking a child in, but that it was difficult without any assistance, especially if children were taken in without any clothing or daily living necessities. The following was explained by some of the participants:

*-“There was not clothes, no food, no nothing, I’m crying when I think about it. The social worker was far away and even if I called he doesn’t come and **it took 10 months, and I got money. I was feeling so bad.**”*

*-“**It is about the grant. I am not working and cannot provide for them financially.** Social Development is **ducking and diving the system.** It is difficult for them to assist these kids. Example these that are showed you are ordered to get back to their mother. I explained that the mother does not want the kids but the social worker informed me that they agreed with the mother. The grant would be taken away until they go back to the mother. And the mother is running away for them because she knows that there is something wrong with them.”*

Durand (2007) found a similar trend in that 37% of his participants questioned the worth and effectiveness of the foster care grants as it was a tedious process and required a long period of time before their application was successful. Considering the urgent need for foster caregivers and the challenges that come with caring for vulnerable children, all efforts should be implemented to ensure that assistance is provided to lighten the unnecessary burden of trying to gain support that should be there in the first place. Non-biological caregivers should be relieved of the struggle to gain support in order for them to focus all their attention on the emotional and developmental needs of their children.

#### 4.4.3.5 Other children and family members in the household being affected

##### (Sub-theme 3.5)

<b>Sub-theme 3.5</b>
How children and other family members in the household are affected
<b>Categories</b> <ul style="list-style-type: none"> <li>• Other children in the household</li> <li>• Other family members</li> </ul>

Various studies have been conducted looking at how the caregivers' own children are affected by foster and adoptive children entering the household. Part (1993) found that biological children of caregivers felt that they gained a great deal from the foster experience, but that they indeed felt a sense of detriment and loss during their own development. Durand (2007) mentioned that biological children showed a sense of rearrangement that affected them negatively and were not always recognised as a significant role player in the foster child's life. Biological children can also be affected by the difference in parenting approach a parent takes on when caring for the FASD child. Jealousy may develop because of time and effort devoted to the affected child. Participants shared the following narratives regarding the challenge of parenting affected children and their biological children:

*-“Um, it’s difficult cos sometimes my kids just say ja, you know if we did that we would’ve got a hiding.”*

*-“She didn’t know any better herself so; sometimes I tend to just remind them. “You know, but because he’s so physically able, it’s like asking someone who’s in a wheelchair to stand up. You know you know that that person’s disabled. I said X’s just disabled in certain areas that he can’t understand, he can’t do or be like you are. So, sometimes we have these little chats and then they kind of understand... It’s a tough life but you know, I can’t help it, it’s just different. X’s just... he’s different.”*

Another finding from this study is that older children may enjoy spending time with the foster children and be grateful that their parents have children in the home again after they have left. They are also able to financially support their parents. A foster mother said this about her son:

*-“My kids do not have a problem... my only son is staying on his own and **he supports me**... My son **does buy and sometimes give money**. He likes the kids and there **were no kids before and I was alone then so he is ok with it.**”*



The research of Durand (2007) showed that the biological children of foster caregivers have a big role to play not only in supporting the foster children but also their parents emotionally, materialistically and monetarily.

Other members of the family such as a spouse and caregivers' own parents may also be affected within the household. These members may not understand the practical difficulties of caring for an affected child which may cause frustration and an increase in stress within the household. Two adoptive mothers shared the following experiences:

*-“They are extremely frustrated cos they do not always understand the FASD child and how... Because the FASD child does one thing today and something totally tomorrow and their age being far more immature of what their age is, my family tend to look at the child and his age and forget that he has FASD, so they they get very frustrated.”*

*-“Uhhh, they are quite...how do I say it? It stresses them out sometimes, most of the time they're okay with it but the things they do not know stresses them out, then they do not know how to handle that when they haven't really learned, they haven't really grasped the concept that it's different with a FASD child and that freaks them out, ya.”*

Caregivers' communications with family members is often limited due to their inability to understand FASD and the struggles associated with this disability (Porty, 2009).

#### **4.4.3.6 The understanding of FASD by extended family and friends and their ability to support the non-biological caregivers (Sub-theme 3.6)**

Upon asking the participants whether their friends and extended family members understood FASD and could offer support to them a noticeable feeling of doubt was observed as seen below:

*-“They do not really support me no, they do not understand it.”*

*-“I think that they do not understand X. Some people just put it down to being really naughty and um lack of control or... and then I've gotta be um hard with him. Not hard as in... what's the word... stern with him. Some people tend to wanna... you know, like my sister will say ag you know is it really necessary and I say you know what it is necessary because if I break it now when you guys go back home um in January then I sit with the problem, because then all of the sudden you broke it now and now a few weeks down the line you do not.”*

Caregivers managed to teach their friends and relatives about some of the aspects surrounding FASD, but there was still a limited understanding as explained by one of the participants:

-“They **understand it a bit and** uhm they are **able to support me in the things I’ve taught them about**, but they’re **very much in denial** “it’s gonna end soon” type of thing, ya.”

It is clear from these findings that extended friends and family do generally not understand FASD and are unable to fully support Non-Biological caregivers.

#### **4.4.4 The utilisation and experiences of a support group (Theme 4)**

##### **4.4.4.1 The need for support in caring for children affected by FASD (Sub-Theme 4.1)**

There was an unquestionable need for support reported from all the participants in the study. Participants feel that they have no idea of how to deal with all the new and continuous challenges they were facing. Porty (2008) concluded that all caregivers for FASD children undertake a role far beyond that which is generally associated with caregiving efforts and this places them in a vulnerable position and in need of vital support. The following narrative clearly states this:

-“I think every... everyone needs comes somehow uh support with um those children... any parent. Any you know anyone that comes in contact with those kids’ needs, they support and **they need advice on how to handle them...**”

Gaining support from other individuals, whether it is a professional person or just someone in a similar situation who understood their experiences, was seen as highly beneficial. Brown *et al.* (2005) supports this by stating that benefits from other foster caregivers with affected children, whether they were less- experienced or more- experienced, was regarded as beneficial for support and educational purposes.

##### **4.4.4.2 Support groups playing a vital role in supporting non-biological caregivers of FASD children (Sub-theme 4.2)**

<b>Sub-theme 4.2</b>
Support groups playing a vital role in supporting non-biological caregivers of FASD children
<b>Categories</b> <ul style="list-style-type: none"> <li>• Provision of emotional and educational support on FASD</li> <li>• Understanding the child better</li> <li>• Ineffective support groups</li> </ul>

Participants responded differently to why a support group was seen as a vital component in supporting caregivers of FASD children. It was clear however, that they saw the support group as both educationally and emotionally supportive, as it helped them understand their child better. The experience of ineffective groups was also reported on a few occasions.

Participants shared that emotional and educational support was important to them. After joining a support group, the feeling of isolation was replaced with a sense of hope and that now they were not alone. They were able to gain *more information about what FASD is*.

*-“Yes, I do. I feel that without that kind of support you... it’s very lonely. You, you find yourself parenting... **your parenting can be very lonely.**”*

*-“I enjoyed it and um, **as long as you can come away with just one thing positive.** And for me I **always did. I actually always did.** So ja, I feel that uh support groups do... did definitely play a feature.”*

Effective/true emotional support is often only available from other individuals who know exactly how you feel and have undergone similar experiences (Porty, 2009). Hudson and Levasseur (2002) found that foster caregivers viewed emotional support as being able to lean on each other. This was experienced by some of the participants as seen below.

*-“Just being **able to share with other people who understand** what I’m going through makes a **big difference** for me.”*

*-“Because we had someone in com... **something in common** (laughs). It was FASD, which is challenging. Where there **were tears you could share cos you really understand.** It’s not something that you didn’t understand. It’s something we understood.”*

The educational aspect that is helpful was also mentioned as an important aspect of why a support group played a vital role in supporting them:

*-“Vir my het dit ‘n belangrike rol gespeel want ek het **nie geweet waarom alkohol sindroom rêrig gaan nie en as ek nie by die groepies by gewoon het nie sou ek nog steeds nie geweet het nie.** Dis hoekom dink ek dis baie belangrik dat jy die groepe moet bywoon.”*

*[For me it played an important role because I **didn’t know what alcohol syndrome really was about and if I didn’t attend the group I still wouldn’t know.** This is why I think it is vital to attend such groups].*

Empirical research completed by Mahajarine *et al.* (2013) indicated that FASD related- information training was crucial as it had a positive association with placements and better outcomes for the caregivers. They proceeded to explain that a stronger understanding of FASD and the unique implications thereof, would be beneficial as it provided a foundation for new strategies that would ultimately have positive outcomes.

Understanding the child better was also a prominent aspect of the support group appreciated by caregivers as it brought a sense of new hope, and changed the way in which caregivers viewed their children:

*-“Like I said, I mean **they taught you... uh, understanding those kids. Really understanding them** and love them and take care of them as best as we can. And how, that’s what the support group did for us. For me personally and I got a... I got a more better understanding for those kids and better respect for them.”*

After discussing how a support group could benefit, a number of participants spoke about their negative experiences in support groups:

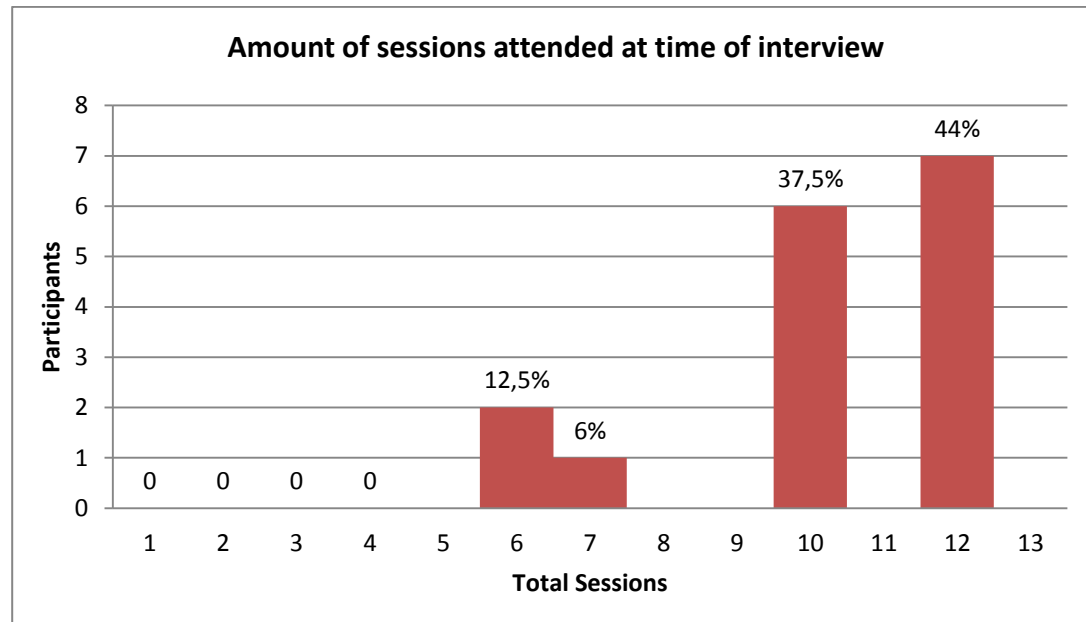
*-“Because **I’ve been trained** with a... I’ve been trained with Y um... I couldn’t get that experience. I was with the with these kids with FASD... uh, I didn’t know nothing. I was blank **but I was trained, I was fully trained. I’ve got certificate... I’ve got five certificates but I was blank blank blank... but after nine times coming to support group I my eyes are wide open, my mind is wide open.**”*

*-“Um, there is not much they know about what you know, understand, all they do is they ask you did you get the safety fee? No, I didn’t get my safety fee. Did you get the safety pack, yes I did...It was not enough information. I do not know how I can explain it. **And we did never know that we would come across these cases.**”*

Research conducted by Cuddeback and Orme (2002) showed that parent training opportunities were often incomplete and unhelpful resulting in negative outcomes such as failed placements. More than 50% of their participants had attended groups where training was offered, but a common thread of incomplete training and lack of resources were found. Similar findings were present in this study with some participants sharing that training opportunities was not successful in helping them.

#### 4.4.4.3 Amount of sessions attended (Sub-Theme 4.3)

The participants were asked to indicate how many support group sessions they had attended up until the date of their interview. The findings are shown below in Figure 4.2.



N=16

Figure 4.2 Amount of support group sessions attended at time of interview

The majority of the members had attended 12 sessions which is consistent with the usual time structure of groups usually ending at about 12 sessions (Sands & Solomon, 2003).

#### 4.4.4.4 Ways in which support groups helped non-biological caregivers to cope better (Sub-Theme 4.4)

A support group helped the participants to think differently about daily burdens and the many causes of their frustration. It empowered individuals by encouraging new thought patterns, helped them gain a clearer understanding of their situation by relating to someone with similar experiences. These all proved to be the most effective ways to help caregivers cope better.

*-“It helped me to cope just by giving me plenty advice and not just, **also just giving advice but uhmm giving you other avenues to explore.**”*

-“Um, they helped **me think differently, deal with realities, deal with my own emotions**. Um, being able to share with other people. Um, getting practical knowledge that I was able to go home and implement.”

-“So, if anything **it just gave me time to understand**.”

-“Uhm **because you learn things that you didn’t know before** and because there was other people that had the same problems like you, uhmmmm ya those are the things.”

Citron *et al.* (1999) agrees with the last narrative by stating that caregivers were enabled to successfully cope after realising that others have carried the same burden and have endured the same challenges. Learning from their peers helped them tremendously.

Another element that stood out was the fact that participants in the group felt a sense of relief when they heard the stories of their peers and came to the realisation that they were not as challenged and had it easier than others in similar situations. It can be seen in the following narratives:

-“Um, well I was just listening to one of the grannies and grandpas who um, have now taken over their grandson and to the funny stories that I would hear about how she’s been handling him. **I started to think yoh you know, didn’t do that, I haven’t done that um...** I would find it funny but now and then this... sometimes you can feel frustrated and sometimes I understood why she’d actually throw a shoe and um, I’ve got the other social worker and her eyes are getting bigger and bigger and bigger. **And I would think to myself I actually you know what we pretty normal.**”

-“We’re still ok. We are ok. So um, again I you know, **you sit and you listen and all of a sudden you kinda feeling how lucky and blessed you are.**”

-“**Ek is nie die enigste ene nie en my problem is ook nie die grootste nie**, miskien het van die ouers met meer hectic problems gesit en ek dink hoe groter jou kinders is hoe meer probleme en hectic raak dit.”

[**I am not the only one and my problem is also not the biggest**, maybe some of the caregivers struggled with more hectic problems and I think the older you get the more problematic it gets].

Porty (2009) agrees with the above findings when stating that hearing the stories of peers and realising that their situations are worse impacts caregivers. This empowered caregivers to identify positive aspects and the strengths of their own families by comparing it to the situations of others who were facing bigger struggles.

#### 4.4.4.5 Meeting the group member's expectations about the group sessions

##### (Sub-theme 4.5)

Fifteen participants (94%) said that their expectations about the support groups were met and one participant (6%) said that she had no expectation, but that she did gain from attending the sessions. Based on the findings the majority of the participants expected to gain knowledge on FASD and how to respond to their children:

-“Yes, I gained knowledge and I am happy to have been part of the support group. **I went there seeking knowledge.**”

-“Yes, I loved it so much it has **brought change in me, it has changed my lifestyle.**”

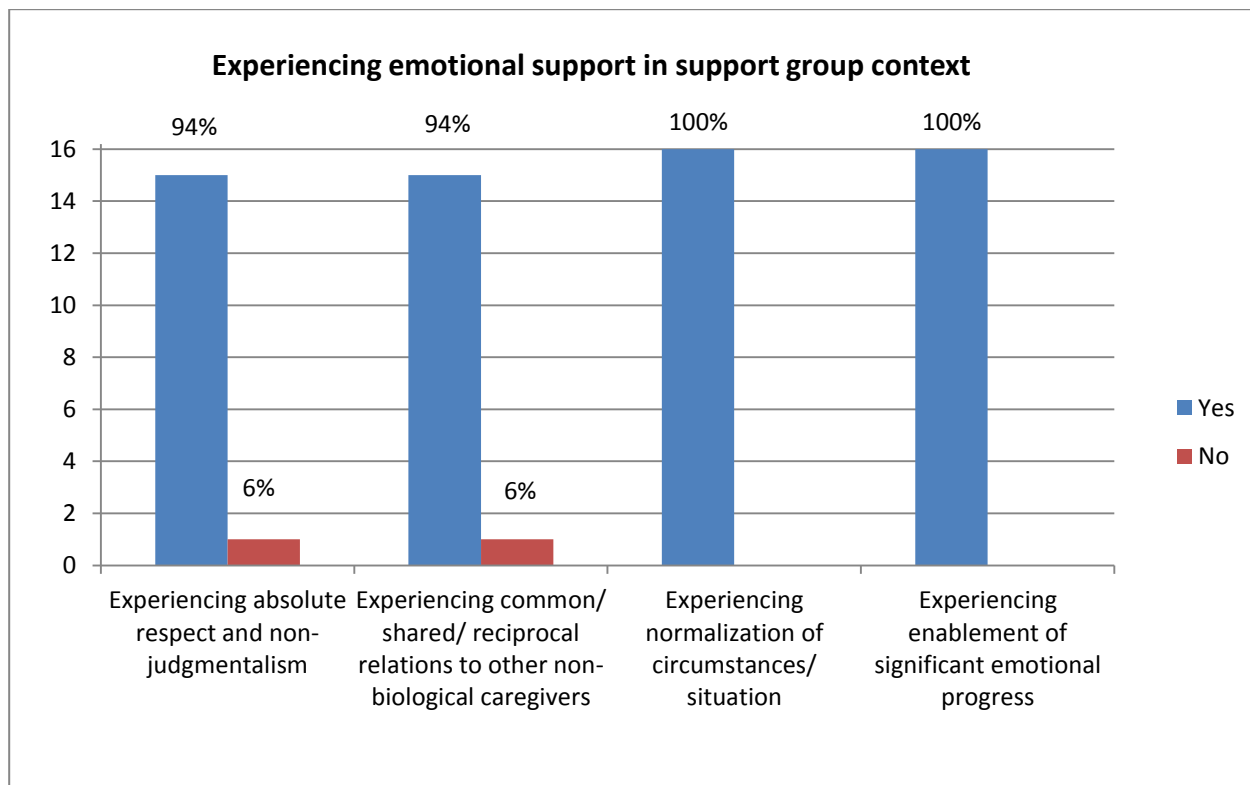
-“It was **greatly exceeded...** I’m seeing the spin off.”

-“Yes they were, **I didn’t have expectations actually**, I went there to see just what it’s like but every session was great and ya they were met.”

#### 4.4.4.6 Emotional support in the support group context (Sub-theme 4.6)

<b>Sub-theme 4.6</b>
Emotional support in the support group context
<b>Categories</b> <ul style="list-style-type: none"> <li>• Absolute respect and non-judgment</li> <li>• Common/-shared/-reciprocal relations to other non-biological caregivers</li> <li>• Normalisation of your circumstances/situation</li> <li>• Enablement of significant emotional progress</li> </ul>

Participants were asked to indicate whether they experienced various forms of emotional support in their respective support groups. They could answer yes or no and provide the researcher with any additional comments on why they chose their particular answer. The findings are specified in Figure 4.3 below.



N=16

**Figure 4.3 Emotional support in the support group context**

A support group can be an essential source of emotional support by providing an opportunity for caregivers to experience absolute respect and non-judgmentalism, a place where they could share feelings that are so well concealed from the rest of the world, a new opportunity to lay bare their worst fears and to vent their frustrations without feeling judged (Porty, 2009). As seen in Figure 4.3 the 15 of the participants (94%) reported that they experienced this in their respective support groups. The following narrative shows a response of a foster mother:

*-“**They didn’t judge me** and I know that they do not judge me you can see by the respect they give you afterwards and **I could blow my top** [laughs] and ja, it wasn’t just like okay well you’re not gonna be able to do it because you blew your top, **they didn’t judge me for that and also by the mistakes I made, you know they just helped me a lot.**”*

In talking about the absolute respect they received in the group, four of the participants spoke about the negative judgement they experienced from community members. This was a sensitive subject due to the fact that these caregivers expected support and encouragement once taking vulnerable



children into their care and providing for them. Instead they were scrutinised and criticised by neighbours and community members for caring for these children.

*-“Die mense verstaan mos nie altyd die kinders nie en um ek het ervaar **somtyds dan dink die mense, hoekom kyk jy na hierdie kinders.**”*

*[The people do not always understand the children and I have accepted that **sometimes the people think why I look after these children**].*

*-“**The community judge me a lot.** “Get rid of the children”. But I cannot live without them. Never.”*

*-“Yes, it seems they are not my biological children and I am really taking good care of them. I allow them to do beatify themselves, make nice hairstyles. **Some people do not even greet me due to their jealousy.**”*

A study conducted by Gottlieb (1982) showed that participants most benefitted by knowing that they had a common relationship with others sharing a comparable burden. The majority of the participants of this study (94%) explained to the researcher that they experienced a common relationship with their fellow group members as indicated by the following narrative accounts:

*-“Um, if I take how I was feeling quite lonely often with things that might have happened with my child at home... um, and the fact that my family doesn’t always understand it **when I shared in the other group and the others would share exactly the same. We were all on the same... we were all fighting the same fight.** Um, and that was just... (sighs) helped me sometimes to just emotionally kind of release myself and they could release themselves and you could just find **comfort in each other.** And then having the information getting back to you on different ways you can deal with it.”*

*-“I would say because then you get to know and you get to know that **you’re not the only one** in it. You’re not alone because you can help each other.”*

*-“I noticed that I **was not alone because when I was in the support group we were sharing our problems and they were the same problems.** I felt good as we were sharing our similar situations.”*

A caregiver dealing with unpredictable situations and on-going challenges can feel like he or she is caught up in an extraordinary situation that no one else will understand. This can become extremely overwhelming and place unwanted stress on the caregiving relationship. A caregiver coming to the realisation that someone else knows what he or she is going through is irreplaceable. The confirmation that caregivers aren’t doing anything wrong or failing in their role as caregivers

preceding the children's unique behaviour was experienced when they saw that their situation was normal (Porty, 2009). *It was a new normal*. The following narrative accounts showed the researcher that the caregivers understood that their *situation was normalised* due to the support group.

*- "...It's normal, because now I know I'm not the only one."*

*- "So, normal, not normal and I've probably learnt **what you think is normal and what other people's normal day is, it's different.**"*

*- "Uhhh because everybody's got the same, the same problem as you with your FASD kids so we all share the same problems so ja to us **that's a normal thing and you get used to it and you're in it.**"*

*- "When we were sharing about children doing things and experiences was like '**oh, wow!**' my child does it and your does too so it's normal to feel like this, it's ok to feel like this."*

Caregivers of FASD children are faced with a reality much different than anticipated or previously experienced with other children. They are faced with the challenges of adapting their environments and finding a new balance. Porty (2009) explained that caregivers shared their stories of re-conceptualising of what is regarded as normal, when considering their FASD child. Caregivers were able to de-stigmatise their understandings and come to the realisation that they were not losing their minds and encountering or creating unusual problems through wrongful actions (Rowbottom *et al.*, 2010).

The challenges that caregivers are faced with in caring for an FASD child contributes to emotional chaos even though the intention is to provide the best possible care. When support is not available and caregivers need to continually deal with emotional conflict and mixed emotions it can lead to burnout (Porty, 2009).

*The enablement of emotional progress* was particularly evident with all of the participants stating that they had experienced significant positive changes in their emotions as a result of attending a support group.

*- "I've learnt not to cry too much anymore [laughs] cause' there was a time I couldn't talk about these kids and I would just cry and I've learnt I've had to **train myself not to do it anymore** because otherwise I'm going to just be a wreck.."*

-“But I mean, you get to a stage in your life like you... **a time you just like calm down**, you do not know what they doing and you know. **And that’s what the support group taught me.** They taught me so much, (laughs) they really do so much. I was like... I fell into pieces every time and I just had to deal with those kids.”

Below a foster mother shared her experience of gaining strength and moving forward from a time where she felt suicidal and unable to cope within her situation:

-“I was a **wreck when I started this programme. I felt suicidal and... felt lost**, because we went through a lot of things there in the township, but the support taught me... really... I cannot pinpoint everything but the person I was a year ago... two years ago... **I’m a more calmer person, a more accepted person.**”

Knowing that others are there to support and listen enables caregivers to access new strengths that help them face extremely problematic situations and what once seemed as catastrophic life events now seem more manageable (Porty, 2009). Support groups play an important role in assisting caregivers to hope again and to grow significantly.

Another important aspect here was in order for caregivers to make emotional progress; they needed to start focussing on the positive aspects and the small success stories of their child:

-“I’ve learnt with M, is just to **take the really small victories and turn them into something really big.** And I’ve just realised that if I keep on doing that with his behaviour at school and with his exemplary work he got to be taken out he was in the top three and I gave him such a **big hug and I made such a big thing about it...**”

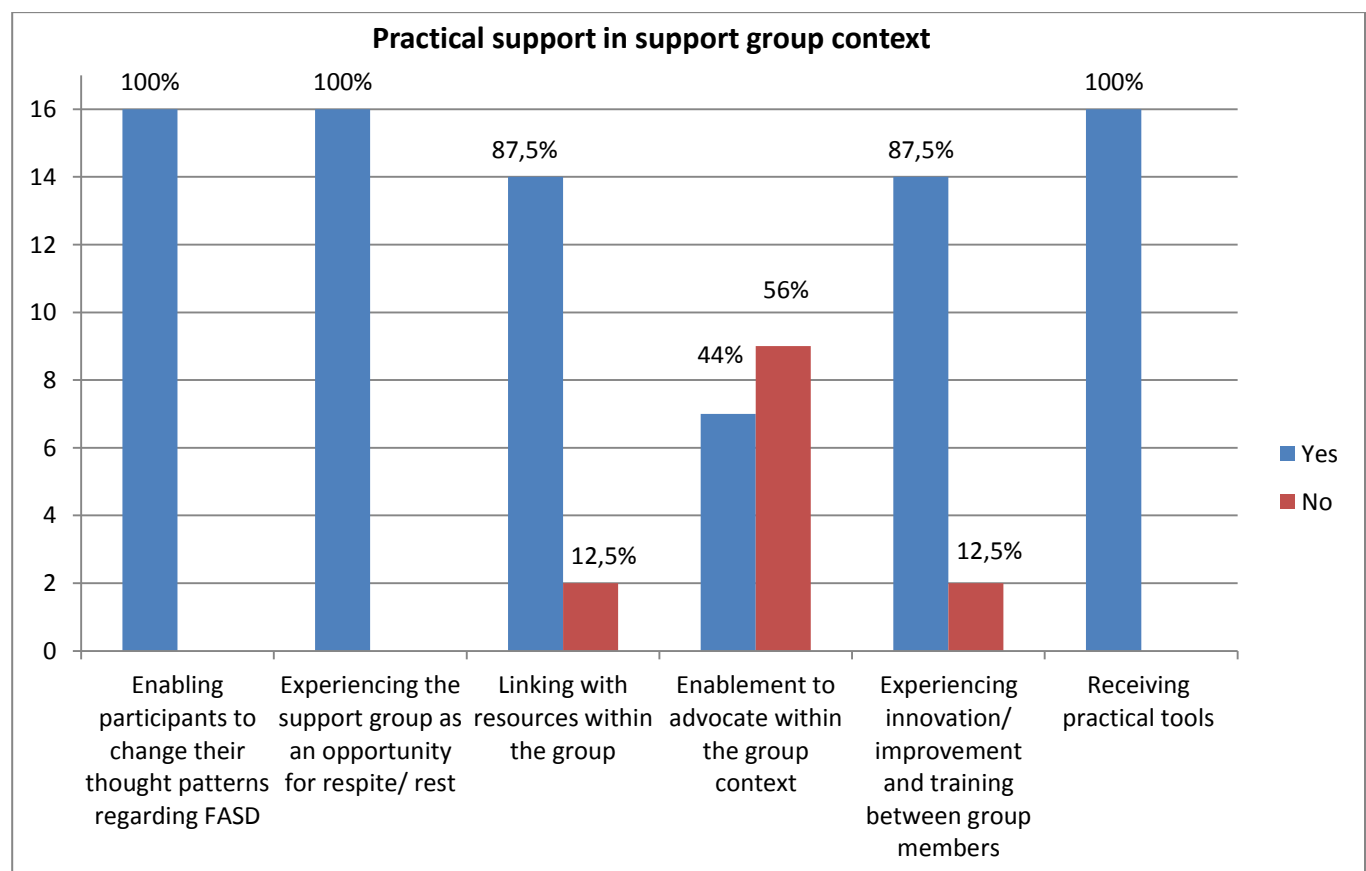
-“**There’s light at the end of the tunnel.** That’s one thing that um I’ve seen. There’s light at the end of the tunnel. **And to be positive, you gotta be positive...**”

-“**Exactly. And I am special and I must take care of myself** to be able to take care of the kids...”

#### 4.4.4.7 Practical support in the support group context (Sub-theme 4.7)

<b>Sub-theme 4.7</b>
Practical support in the support group context
<b>Categories</b> <ul style="list-style-type: none"> <li>• Enabled to change thought patterns regarding FASD</li> <li>• An opportunity for respite/rest</li> <li>• Linking with resources within the group</li> <li>• Being able to advocate within the group context</li> <li>• Innovation/improvement and training between group members</li> <li>• Receiving practical tools</li> </ul>

In addition to emotional support, the researcher wanted to determine whether caregivers received *practical support* within their support groups that could assist them in their caregiving roles. The findings are shown in Figure 4.4.



**N=16**

**Figure 4.4 Practical support in the support group context**

There was positive feedback across all six identified forms of practical support and caregivers generally showed gratitude towards the support groups for helping them become more realistic and practical in caring for their children.

All the participants indicated that they were able to change their thought patterns regarding FASD. What was once was seen as a problematic child was now seen as a child who often faced challenges beyond their control. There was a clear change in all the participants. They appeared to have changed their thought patterns surrounding the behaviour of the child:

*-“It has helped me a lot because in the past **I used to think they are doing things because they are mischievous but now it is because of the FASD.**”*

*-“Ja, ek het, want um, ek sou **nou as ek nie geweet van FASD nie het ek maar net gedink sy’s stout en lui en so, en dit het nogal verander met die leer van dit.** Daar is ‘n deel van jou brein wat komplikeer, wat nie werk nie.”*

*[Yes I have, because um, **if I didn’t know about FASD I probably would have kept on thinking that she is naughty and lazy and so, and that has changed with learning about about this.** There is a part of your brain that is complicated, that doesn’t work]*

*-“Yes, like I said **I’ve changed my thought patterns and stuck to it.**”*

Experiencing the group as an opportunity for rest was also felt by all members. Various reasons were given for this; getting away from the daily routine, sitting in the company of alike adults, being able to sit without having to attend to a child or a crisis and receiving spiritual/religious input greatly helped caregivers. The following comments show this.

*-“Just to **get out of normal daily routine** and be with other adults for a change ja.”*

*-“It was my holiday for the day. **It was my holiday for the day** when I come support group.”*

*-“Like I feel... it taught me a lot **and I feel renew and I feel spiritually uplifted.**”*

*-“**We relax.** Those two hours you sit in the chair and you relax.”*

*-“Hier het jy gekom en gesit en gesels en ‘n koppie tee gehad en ‘n koekie gehad... dan voel jy rustig want **jy sit en relax as wat jy by die huis is, moet jy heelyd op jou tone wees.**”*

*[Here you came and sat and spoke, you had a cup of tea and a biscuit... then you feel calm because **you sit and relax as opposed to home, where you are constantly on your toes**].*

Linking with resources enables group members to find out more about relevant and available resources outside of the support group and guidance on where to find them. There was an interesting finding in this study. Participants viewed each other as resources due to the lack of services available to assist them. The majority of the participants responded to this question by talking about how the opinions and advice of other group members, including professional people who guided the group sessions, were important resources to them.

*-“Ja, hulle het vir ons dinge gesê soos wat hulle probeer het en dan as jy dit probeer en kyk of dit werk vir jou kind, **jy het maar net so kyk mekaar uitgehelp...**”*

*[Yes, they told you what they have tried and you tried it to see if it worked for your child, you **just helped each other out like that...**]*

The change in thought patterns regarding resources is explained by Porty (2009) as the heavy investment in the lives of one another and the generation of ideas internally when there is a lack of available resources in the community.

Two participants who reported better access to resources and that they had gained a lot of information through their own research efforts on the disability prior to the support group felt like the group did not provide them with additional resources.

Advocating for children struggling with FASD can have significant effects in the community (Porty, 2009). As much as it can be a group effort, advocating as an individual could also be effective. Two main ideas of the form advocacy came to the fore during the investigation and it was interesting to see how the residential status changed the idea, understanding and execution of advocacy.

The first form advocacy that was prominent with the specific participants living in the informal settlements was their urgency to share the new information that they gained with as many people possible; they went from being educated to becoming educators. It didn't matter how the information was carried across as long as they could tell as many people as possible:

*-“The neighbours... I’ve been uh telling the people who are pregnant and drinking, who are pregnant and smoking... **I told them, I explain.**”*

*-“But now, I will... I can teach other people, I... **I feel like they can knock on my door now and ask for help.**”*

-“Ya, it’s like **I would like to teach especially the youth, ne about the dangers of drinking when they are pregnant.**

-“I could you know **give them a little bit of a rundown of what it is and what it’s about** and you know because a lot of people do not know about it people’s you know when you see their reactions how shocked they are and **it made me feel good to be able to tell them about it.**”

Participants of this study who were more educated and empowered in the field of FASD saw advocacy as a more formal and bigger scaled activity:

-“Um, I think once everybody actually understood FASD and then started actually going into their own communities and talking more about it. I think that a group could develop into something cos then it’s carers who actually now understand and through their experience who are now able to rise up and start advocating for children and caregivers like. **But I think it will have to mature, it’s not something that’s gonna happen in the first 12 months...**”

A particular participant was excited about the fact that her suggestion of an information workshop in the community was successfully executed:

-“Well, I suggested that we have a work day maybe **a workshop for our family and whoever that is involved with our kids and the organisation ran with it yes and we did it...** I felt good because I thought you know just by opening my mouth and suggesting that you now it, **it was noted that we could do that and it worked.**”

A second idea that came forth was the desire of many participants to respond to the calling they felt in furthering the cause of FASD and helping those affected by this disability, even if it was only still a dream;

-“I think... and, maybe from my side as well... I had this experience, **I must build something inside my house or somebody else’s house and then we can, you know, do things like that as well.**”

-“Um **my dream is to extend my house and turn it into an orphanage or crèche only for FASD children; I want to take care of them.** I’ve already got my NGO which I call the rock of ages, I have the certificate and I will register at the end of this year and next year I will start operating. And um, I would also like as I told you, I would like more training so that I can teach it this to the other people in the other organisation. I will also ask them to teach some other people because this is a danger in this world for these children who are abusing alcohol because they are killing the the new generation because what if they are all drinking and what will happen to the world if all the children have FASD.”

***-“We were planning of starting the meetings with community as we are also having group of social workers who comes to my house. This means that we can extend it out.”***

Through the exchange of information and facts group members assume the role of innovators and training-agents. Sands and Solomon (2003) explain that groups provide members with the opportunity to exchange information such as knowledge of the disability, skills on dealing with behaviour, techniques for problem solving, and strategies for coping better. Through this process of information sharing members become each other’s teachers and inspire each other to improve themselves and their situations. The following narratives show this:

***-“It helped me a lot because each one would give there information of how they were looking after their kid... we would give each other’s information and help each other and give each other advice.”***

***-“...Ek het baie geleer van die mense van wat saam met ons hier was, ek het baie geleer en van Y het ek baie geleer, soos ek sê die dinge wat ek verkeerd gedoen het ek by hulle kom leer om dit reg te doen.”***

***[I learnt a lot from the people that were here with us, I learnt a lot and from Y I learnt a lot, like the things I did wrong I could come to learn from them how to do it correctly].***

***-“Um, ons kan mekaar advice gee. Verstaan jy nê kan ons vir mekaar advice gee, daar is somtyds baie dinge wat ek weet of wat iemand anders weet wat ek nie weet nie dat hulle vir my kan sê: Het jy al dit probeer, het jy al dit getry met X, met X is daar altyd raad wat ek soek.”***

***[Um, we could give each other advice. Do you understand there was something that I knew or that someone else knew that I didn’t understand and they could tell me: Have you tried this, or have you tried that with X, with X there is always advice that I seek].***

Citron *et al.* (1999) summarises this concisely by saying that peer information is fathomable and that it stimulates understanding which opens up new possibilities for fruitful life change.

Since practical application is crucial, the researcher wanted to determine whether the participants had received any physical or practical tools that they could implement in their homes and 100% of the participants agreed that they did and that it greatly contributed by helping them adapt their home environments. It can be seen in the following narratives:

***-“And we got lots of, lots of tools different tools. Um, that was really... that was very effective when we actually implemented. Not all the tools always worked coz FASD children differ and you had to go home and adapt it to each child. But the tools were definitely worth trying and using and they were able to be used.”***



*-“We would talk about the charts, what foods and we have like games and you’d say what food you’d have to feed them, how their rooms have to look like, charts like that for instance. Uhm everybody would get their ideas and tell you how, we would tell each other the routines we would use.”*

#### 4.4.4.8 Approaches in support groups (Sub-theme 4.8)

<b>Sub-theme 4.8</b>	
Approaches in support groups	
<b>Categories</b>	
<ul style="list-style-type: none"> <li>Assisting caregivers to utilise their own strengths (MA)</li> <li>Feeling like part of a community within the support group (MA)</li> <li>Teaching the purposeful use of self (MA)</li> <li>Participants feeling like they had something worthwhile to offer to the group (MA)</li> <li>Being able to talk to and listen to your fellow group members (MA)</li> <li>Discussing taboos and forbidden topics within the group (MA)</li> <li>Feeling like others are “in the same boat as you” (MA)</li> <li>The support group as a helper in facing difficult situations and coming up with new viewpoints and strategies (ED)</li> <li>Being able to problem solve better as an individual (ED)</li> <li>Role play taking place (MA/ED)</li> <li>Gaining better insight and understanding of FASD after attending a support group (ED)</li> <li>Being provided with relevant information that caregivers could apply in caring for affected children (ED)</li> </ul>	<div style="border: 1px solid black; padding: 5px;">           Mutual Aid Approach (MA)            Educational Approach (ED)         </div>

The researcher wanted to find out what approach support groups for non-biological caregivers of FASD affected children utilise and reviewed the mutual aid approach (MA) and the educational approach (ED). A series of questions were asked to identify whether or not participants had experienced both.

Emphasis should be placed on staying focused on what group members can use to benefit their fellow group members and to successfully negotiate their world through the use of *personal strengths*. Every individual will have something positive that works in their favour and by helping them to realise this, they will be empowered to apply these skills in a manner that helps them develop positively (Steinberg, 2004). All the participants of the current study had felt that the support group had helped them in identifying and utilising their own strengths.

*-“I came here to the support group... Eh I I’m looking after the kids I love children but now I’ve **been motivated**... I even gained more now it’s not gonna change, it’s not gonna stop.”*

*-“I love them and I was inspired to love the kids more.”*

*-“Well, it was very... **it it made you focus on yourself**. So, if you look at what we did there were times where you could look at yourself and you had to find the good in you to be able to carry on. **So you got a lot of affirmation** in that you can do this and it did carry and help me ja...”*

The FASD support groups that the participants attended seemed to achieve what Brown *et al.* (2005), states regarding the responsibility of social service agencies attending to and building on the strength of individuals and families and so develop their resiliency.

Feeling like part of a community assists individuals to open up to and face situations with others who are able to relate and understand them, due to similar experiences. A support group provides opportunities to share experiences and look at new possibilities that may not have been considered before. Individual members develop a support network and ultimately a supportive community (Sands and Solomon, 2003). Two participants described their experiences below:

*-(Laughs) Um, being a carer of a FASD child it’s uh it’s very lonely and it is kinda we developed our own little community. It’s just start finding things together, laugh about, joke about. **Just got your own sense of community.**”*

*-“I didn’t just feel as community, I felt as family.”*

The purposeful use of self is achieved when group members are enabled to re-examine their past experiences and have the opportunity to celebrate their achieved success, as well as the opportunity to learn new skills as they reflect, revise and consider less successful stories (Steinberg, 2004). Participants in the current study reported experiencing the above and most of the participants specifically mentioned learning how to calm down and not lose their tempers as easily anymore:

*-“No, they taught me how to **have patience with the child and understanding.**”*

*-“Um, to stop and think before reacting, because I’m... I’m the kind of person that just reacts so quick. **Just stop; try to think first and then discipline.**”*

*-“Without support group I wouldn’t know these steps. I would keep on shouting to the child. Sometimes smack a child, **but now I’ve got experience**... without experience we wouldn’t know nothing.”*

*-“Definitely, it did because each one, I mean the kids could make you mad, the kids could make you want up the wall, the kids could want to make you pull your hair out or grab them and it taught you how to control yourself. Self- discipline. ”*

*“I learnt that I must to control my temper because before I used to explode but now I am more calm. I know how to deal with it.”*

The participants agreed that the support group has helped them realise that losing their temper and screaming at the child was not helpful and that they also learnt to practice more calm behaviour.

In order for the group to grow and be successful members must commit to being open and willing to share of themselves whether it is good or bad. A sense of feeling like participants had something to offer to others, gave them a sense of obligation, they felt that they were there for the well-being of others’ as well as themselves. Being able to see that they had something valuable to add to the group also allowed participants to identify and develop their personal strengths. Participants were asked to identify what it was that they thought they had to offer. Some of the responses were as follows:

*-“Um worthy advice and love.”*

*-“I think my experiences with my children were my... I could **speak out of my own experiences** and from listening to others, so I could associate and I could find common ground.”*

*-“The **knowledge I have, my dreams and my views**, and my um **my experience**.”*

*-“If you’ve if you’ve worked with a FAS child, if you’ve lived with a FAS child, um you **speak out of experience**. It’s not always what... what the books say is not always the reality of when it actually is with the children. So, you speak out of experience.”*

*-“I’ll probably just... humour (laughs).” “Uh no. I do I... **I care about people**. I feel like I throw myself in sometimes so deep that I wonder why did you... why do you... you know, I jump from the oil right into the bloody fire.”*

A certain participant also shared that she had knowledge from work experience and research in this particular field that was valuable to other group members;

*-“I think for me personally because I was so much further... I’m **more advanced than all of the others in the group cos I’ve done the research and I’m part of X**... um, not for me personally... um, in... cos a lot of the stuff I already know... **but I think I was able to help them**.”*

Gitterman and Shulman (2005) describes the dialectic process as one where one or more of the members develop an idea, an opportunity is provided for the idea to be challenged and all group

members are then allowed to form their own opinion regarding this. For this to be achieved group members have to feel that they are able to listen and speak and that attending a support group is not just a one-way communication channel. This can be difficult for more reserved and shy group members. One participant shared her experience of growth below:

*-“Jy kan praat oor jou probleem en almal luister en so dit het vir my gevoel okay, soos ek sê die eerste keer dit wassie maklik nie maar die tweede sessie en die derde sessies het makliker gegaan tot ek kon amal noem op die name en gesels [laughs].”*

*[You can talk about your problems and everyone listens and that is how it felt for me, like I said the first time it was difficult, but after the second session and the third session it got easier and I could call everyone on their name and talk].*

*-“Ja, um, sommige tye as ons in die groep gewees het en ons het beurte gekry om te bespreek watter challenges ons deurmaak en ook om te luister na die ander moeders se challenges wat hulle het, het dit vir my meer rus gegee.”*

*[Yes, um, sometimes when we were in the group, we had turns to discuss which challenges we face and to listen to other mothers and the challenges they face, that gave me peace].*

It is evident in research that caregivers of FASD children are often faced with the reality that they were unable to discuss issues in other contexts apart from their support group (Porty, 2009). According to Gitterman and Shulman (2005) taboos are those unstated norms of behaviour in society that forbids honest discussion about our fears and concerns. Participants in this study came up with three main topics that were regarded as taboo.

The first being forms of discipline. Since ruling passed that corporal punishment is no longer allowed as a discipline method for children belonging to the state, the topic of how to discipline came up within the group context. The majority of the participants were raised differently, mostly experiencing corporal punishment growing up. It was difficult for some participants to refrain from using this method and utilise other methods of disciplining children. Physical punishment was also shown to be less effective with children struggling with FASD. The following was shared by participants:

*-“Ja, ek dink oor um die kinders wat nie meer mag pak kry nie. Ek dink dis ‘n groot ding in in die omtrek dat ‘n kind nie meer mag... En ja, partykeer is ‘n pakslae maar so nou en dan nodig, maar jy mag dit nou nie maar ons kon dit bespreek en almal het maar hul opinies gegee daaroor en so aan.”*

*[Yes, I think the fact **that children are not allowed to get hidings anymore**. I think it is a big thing in the environment that the child is not allowed anymore... and yes, sometimes a hiding is necessary, but you are not allowed to, **but we could discuss this and everyone could give their opinions**].*

*-“Within the group, we some us... some of us in the group... some of the people in the group’s... their **method of disciplining would normally not be something used that you would discuss in public**. And they never have a place where they could actually share their frustration and it went out in some of the people the ways they disciplined the kids. And it was discussed openly and nobody actually felt scared or threatened that they’d be in trouble for it. And the others were able, in the group; to say you know but you... you can’t be doing that because that... you could get into trouble for it, this is the alternative.”*

The second taboo subject highlighted was inappropriate sexual behaviour displayed by the affected children. Caregivers were often embarrassed and extremely concerned about the inappropriate sexual behaviour that their young children displayed. The support group provided them with the opportunity to speak about this and learn that this is a common phenomenon with FASD children and that they are not alone in this regard.

*-“That I thought that they would not, ya I will talk **say about their sexual fantasies**.”*

*-“Mmm, ja okay sê die seks, **laat die kinders meer um oop vir seks hulle gedrag, hulle seksuele gedrag wat nou FAS met is**, kom daai gedrag nou sommer op ‘n stadium na vore.”*  
*[Mmm, yes okay I **would say sex, which the children are more open to sexual behaviour, their sexual behaviour because of FASD**, which behaviour comes up at a certain stage].*

*-“There was two... the two things that comes up is, one, is the discipline, because a lot of the caregivers who work with FAS children lose it and then they feel it and then, of course, the **sexual side of it. Um, because of the inappropriate sexual behaviour. Um, and it comes up often with the kids that caregivers actually were able to start discussing it.**”*

The third taboo subject raised was that children were often involved in taking things that weren’t theirs. Participants reported feeling embarrassed of their children who were caught stealing things;

*-“And the fact **some of the children steal**, was also a **big problem that they do not like talking about**. And that came up and were... we were able to discuss it and dealt with...”*

Once members realised that they were ‘in the same boat as others’ they felt more at ease and provided an opportunity for sharing (Steinberg, 2004). Participants were all convinced and relieved even if their individual experiences were unique and diverse.

-“Totally, And that **just because the way we all shared** (laughs).”

-“Ek dink so ja. Ek dink **ons almal het in dieselfde bootjie geval en ons moet daardeur swem en ons het daardeur gekom** (laughs).”

[I think so yes. I think all **of us fell in the same boat and we must swim through this and we got through this**].

One participant mentioned that she recognised them all to be caregivers who wanted the best for their children. They are all going through the same things, experiencing the same challenges, trying to be the best they can be for the child in order for them to receive the care they have never experienced before:

-“Want ons is almal foster caregivers. ons is almal deur dieselfde fase gegaan, ons het almal deur dieselfde probleme gegaan, **ons het almal probeer om van daai kind ‘n beter kind te maak en ons het almal hard probeer om ‘n goeie foster ma vir daai kind te wees en vir daai kind te doen wat sy ouer of sy mense wat hy by gewees het nie kan gedoen het nie.**”

[Because we are all foster parent.. we all go through the same phases, we all went through the same problems, **we all tried to make that child a better child en we all try to be a good foster parent and to give that child something that his people with who he was could not give**].

An interesting topic that came up a few times was that no matter where one resides, the experience is the same. Participants said that they were affected by FASD no matter in which residential area they stayed. This disorder is not just prominent in informal settlements, it is found everywhere.

-“And for **me to be in a township and for another member group that stays in a house** in Y for instance, or you know... or town... we could understand they all... they all experience the same problems with those kids. **Doesn’t matter which area you stay at or where you stay, we always experiencing problems.** And it was always about the kids and not where we stayed.”

New strategies and viewpoints are important pre-requisites to change behaviour. The support group can create a conducive environment in which members are equipped to face and deal with situations that have plagued them up to now. It allows them to reflect on themselves and to see how they relate to these situations. In order for this change of behaviour to occur emotional support alone is not sufficient. Group members need to open up and then be practically supported when facing difficult situations. This can be a slow and difficult process but is achieved through the dialect process in the group context (Steinberg, 2004).

-“**Strategies, but then also within that, the information given to me also helped me to get new view viewpoints**, well I was forced to get new viewpoints by actually participating in the actual programme. So, mm... a lot of the stuff I knew but because I was now forced to go back and implement.”

-“Definitely, **there were always new view points, new strategies because somebody would listen to you...** ‘Oh that’s right, I should have done it that way, ah I can do it that way’.”

-“Hmm, the group helped me **face difficult situations...** just by teaching me, showing me and helping me and giving me advice on how to deviate from a specific situation to draw the attentions away and try other avenues and things like that.”

-“Um, **they helped me think differently, deal with realities, deal with my own emotions.** Um, being able to share with other people. Um, getting practical knowledge that I was able to go home and implement.”

One participant reflected that facing these situations and coming up with new strategies does not always come easy:

-“Um, I think there was things that maybe at times you not ready to deal with... some realities you got to face. **Um, and so then sometimes you have to decide whether you actually were open to it or not.**”

The value of strategizing with fellow group members in a support group context even if it is not successful in implementation, helped make participants aware that they are not alone in their struggles and that change is good. It highlights the importance of the strategizing process and development of new viewpoints (Porty, 2009).

Being able to problem solve better as an individual is one of the educational groups’ objectives. Upon asking participants whether they were able to do so through their participation in a support group, there was resounding agreement. Members were encouraged to go home and implement their newly gained knowledge and strategies where there were no members to practically support them. Although this was not always an easy process for participants, successful stories were recorded as seen below:

-“Just because of all of the above that you **basically learn to deal with certain problems in a certain way.**”

-“I can **step back and I can look at problems from a better view.**”



-“Yes, but ***I am still challenged.***”

In the study conducted by Durand (2007) he found that role play was tremendously fruitful in creating a sense of consideration amongst caregivers and that a greater understanding of the different sides of issues was highlighted. Sands and Solomon (2003) also stated that group exercises such as role-plays allow the creative involvement of members in each other’s problem solving attempts.

All of the participants in this study reported that they were involved in role play activities and that practical learning did occur. One of the participants, however said that although she participated in role playing exercises, she did not enjoy it:

-“Ja we did have but ***I wasn’t comfortable because I found it difficult sometimes.***”

There are various reasons why individuals may attend groups. This could include, to gain support, finding a solution to specific struggles, locating others who share similar experiences and learning more about particular issues faced during a certain process. The researcher wanted to establish whether participants felt that they had gained overall better insight and understanding of FASD after they attended support groups. All of the participants indicated that they had indeed achieved this. Many of the participants initially had no idea regarding FASD and what it entailed and attended the support group mainly to learn more about this disability. Other participants initially presented a basic knowledge of FASD and primarily wanted to learn how to better manage their households and how best to deal with difficult situations associated with this disability. Being able to relate to others who experienced similar situations provided participants with the opportunity to learn from first-hand experience. Participants further gained by attending well-planned sessions with professional persons and guest speakers who helped them understand their situation better.

-“Ek het ***baie verstaan, ek het baie geniet om hier te wees en as ek dit weer kan doen dan sal ek dit weer doen om nog meer inligting te kry.***”

[***I understood a lot, I enjoyed being here and if I can do it again then I will do it again to gain even more information***].

-“The topics that we dealt ***were relevant to what we needed***, what I needed as a carer. It ***wasn’t just um, facts and information, stuff I could go implement.***”



Mahajarine (2013) showed that the caregivers benefit from the support experienced and that there is improvement in their overall knowledge and the ability to better care for affected children. Whilst the challenges aren't entirely removed there is however a hopefulness to utilise new ideas and approaches.

Being able to apply newly gained knowledge is important in helping bring about change in the home environment. Group members should be empowered and encouraged to apply this new knowledge at home in order to make it part of their daily functioning. They should then be able to adapt themselves in such a manner that they are able to meet the needs of the FASD child. The researcher wanted to establish whether participants were provided with such relevant information and if it was applicable to their caregiving roles. All of the participants were in agreement that they were empowered by the provision of very practical and applicable information that they could take home and implement. Some of their comments are given below:

*-“It helped me as **we are provided with lots of information to read when I am at home.**”*

*-“No. Uh, if I if I think about the **homework activities and things we were given to go home and do, you had to look at yourself.** You had to find a way to go back and work with it. So, ja no it gave... **it was purposeful.** It wasn't just, you didn't get just something you had to go home and guess you **had to actually go home and implement it and see...** plan it through, see it through and see that they happening. **It's... It gave a lot of direction.**”*

*-“Ja, ek dink net vir my wat niks geweet het nie... Ja ek het meer geleer oor hoe om met haar te werk en **hoe om te fokus hoe om dinge rondom haar en die familie te doen.**”  
[Yes, I think for me who knew nothing about... Yes I have learnt more about how to work with her and **how to focus on doing things around her and the family**].*

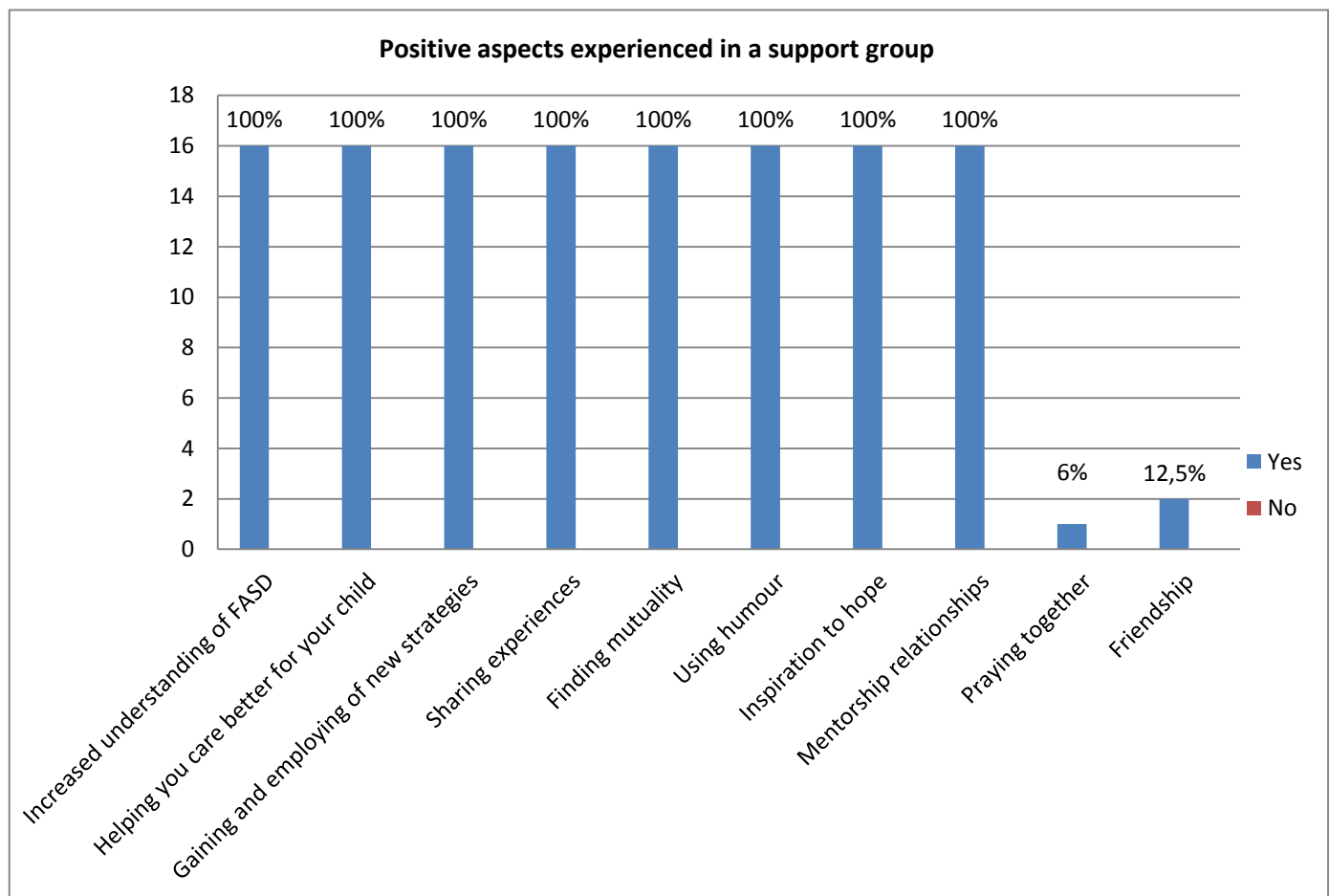
It is evident from the discussion in this section that non-biological caregivers recognise the value of and benefitted from both an educational approach and mutual aid approach. Education was offered in the form of information sharing opportunities with each other and was also presented by professional persons. This given information was not only new to most participants, it was also liberating to them. This liberation resulted in a sense of freedom to explore new avenues and to gain more as they continually participated in the support group. The mutual aid approach was achieved through the provision of support from others who were in the same boat as them, by others who

respected them and reinforced their strengths and experiences. Participants were able to develop their own sense of community; a safe environment in which they could debate, the ability to look at new perspectives and help each other devise new and appropriate strategies. Support groups that build on educational components and devise potential intervention strategies for a particular disorder all within a mutual aid environment have proved to bring about participation satisfaction among its members (Hagen & Gallagher, 1997).

#### **4.4.4.9 Positive aspects within a support group (Sub-theme 4.9)**

<b>Sub-theme 4.9</b>
Positive aspects within a support group
<b>Categories</b> <ul style="list-style-type: none"> <li>• Increased understanding of FASD</li> <li>• Helping to care better for FASD children</li> <li>• Gaining and employing new strategies</li> <li>• Sharing experiences</li> <li>• Finding mutuality</li> <li>• Using humour</li> <li>• Inspiration to hope</li> <li>• Mentorship relationships</li> <li>• Praying together</li> <li>• Friendship</li> </ul>

Participants were asked whether they experienced some of the following positive aspects within their support group environment. Various aspects were listed for the participant to choose from but participants were again encouraged to add any additional aspects or comments if they so desired. The findings are shown below in Figure 4.5.



**N=16**

**Figure 4.5 Positive aspects experienced in the support group context**

All participants stated that they gained an increased understanding of what FASD is after attending the support group sessions.

Another interesting finding that came to the fore was that, many participants reported how their traditional views about what this disability entails and how it is caused, have changed. For many participants the children struggling with FASD were seen as having been influenced by evil spirits or described as just being stupid. Participants explained that these thought patterns had changed after learning more about the disability.

*-“Teaching us all those things make us happy because we didn’t know how to handle cases like this and because we didn’t know even how... we thought **maybe this boy is bewitched, this boy is cursed or something like that.** Now you made us think, take these things another way around. **We do not have to be thinking all these funny evil reasons.**”*

*-“It was this sickness and in the olden days, the old woman were drinking alcohol, and this gin understand, this thing was there long time ago but we didn’t know what it was and at school some of these **boys are stupid**, we called them stupid, we didn’t know what was happen and they did never get help because we didn’t know what was happening. **But I am very happy that I went through this course and now we know exactly what is happening.**”*

Attending a support group had also reportedly helped all of the participants care better for their child which is similar to a finding reported by Leenaars, Denys, Henneveld and Rassmussen (2012). Their study reported that 32% of their caregivers managed to handle their children better after participating in a support group. Another study conducted by Mahajarine (2013) also reported that 67% of the participants in his study presented increased knowledge of all aspects surrounding FASD post a support programme.

Upon asking caregivers if they employed their newly gained strategies all the participants were able to confirm that they indeed learnt new strategies and that they did implement these at home.

*-“Now I know how to handle kids especially when they misbehave and how to help them in that situation. I used to stress much but not anymore.”*

Porty (2009) reinforces the above narrative statement in saying that positive results of support groups in her study were due to the implementation of practical strategies in dealing with stressful encounters and as a result being able to maintain better control.

All of the current participants felt that they shared their experiences with the rest of the group and that their sharing was respected and accepted by the rest of the group.

Finding mutuality was experienced by all the participants and it became evident that the support groups were regarded as an important support system in which they could relate to others through sharing and listening.

Upon asking group members about *the use of humour* in their support group, every participant gave a little laugh and answered yes. Laughing is seen to be an effective coping mechanism in the midst of stressful situations (Porty, 2009). It was clear from the participants of this study that laughing with others about things they found most difficult and unpredictable, helped them greatly.

*-“Ons het **gelag** en gehuil.’  
[We **laughed** and we cried].*

*-“Ja dit was eintlik dieselfde challenges wat ons deurmaak en **ons kan lag daaroor**. Wat jou kinders aan gevang het (laughing).”  
[Yes it was actually the same challenges we were making through and **we could laugh** about it. The things your children were up to (laughing)].*

All of the participants were *inspired to hope again*. It was evident by listening to the participants share about their successes and how they received unconditional support from those who really understood them, that they now experience a sense of hope that things will get better for them.

All of the participants felt that *mentorship relationships* were formed. This usually results in some of the members being more knowledgeable and experienced than others who are able to guide the rest of the group in strategizing and problem solving opportunities. The participants of this study said that they did experience mentorship relationships by listening to each other and to the professional individuals responsible for guiding the sessions.

*-“I’ve never known how to handle certain situations and with the support group as you know **Y as the psychologist that was there would tell us exactly which way to handle the situations and he would guide us and tell us exactly.***

The two other positive aspects that were identified was being able to *pray together* and finding *friendship*. Participants stated the following:

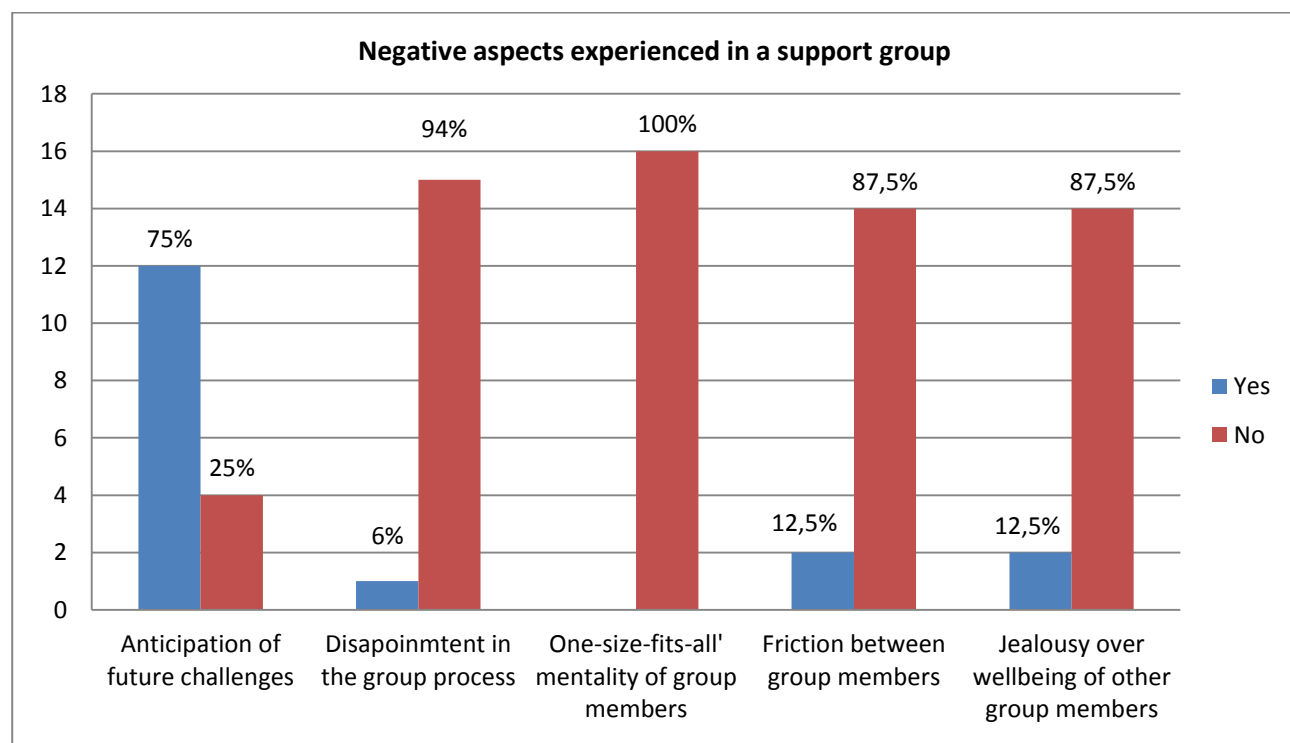
*-“I think we **left there as friends.**”*

*-“Yes, I notice something that puts us all together before attending we were not friends but due to being part of that group we become closer. We knew each other before and there were tensions and not a close friendship. **After the first session we were not talking but now we have developed a bond of being caregivers and we appreciate each other...**”*

#### 4.4.4.10 Negative aspects within a support group (Sub-theme 4.10)

Sub-theme 4.10
Negative aspects within a support group
<b>Categories</b> <ul style="list-style-type: none"> <li>• One-size-fits-all mentality of group members</li> <li>• Disappointment in the group process</li> <li>• Anticipation of future challenges</li> <li>• Friction between group members</li> <li>• Jealousy over the well-being of other group members</li> </ul>

Participants were asked whether they had experienced some of the following negative aspects listed below. Their responses are captured in Figure 4.6. Participants were required to answer yes or no and then given the opportunity to add any additional aspects or comments if desired.



N=16

Figure 4.6 Negative aspects experienced in the support group context

The majority of the participants said that they anticipated future challenges after listening to the situations of others:

*-“Something is going to happen because when they grow up something will change. **But I’m fit for it because I know that it is going to happen.**”*

*-“Ja, ek het so iets nogal verwag ja (laughs), ek het.”  
[Yes, I did **kind of anticipate yes** (laughs), I did].*

Citron *et al.* (1999) concurs with this finding as caregivers come to realise that their difficulties will increase as time goes by and the children grow older.

The majority of the members indicated that they did not experience disappointment in the group process and mostly showed gratitude towards being able to participate in such an opportunity.

All of the group members reported that they never experienced that a ‘one-size-fits-all’ mentality was being imposed on them. That was an interesting observation as this aspect can often be experienced in support groups when carers share a similar situation (Porty, 2009).

Upon asking whether participants ever experienced friction within their support groups, two (12%) of the participants said that they did. Both of the participants said that the friction was caused due to disagreements in opinions and even though it happened, it was seldom and was sorted out between group members.

Jealousy over the well-being of other members can often be found in support group contexts especially when particular members are better equipped or have better access to much needed resources (Porty, 2009). Two (12%) participants said that they experienced feelings of jealousy at times.

#### 4.4.4.11 *Recommendations or changes for support groups suggested by non-biological caregivers (Sub-theme 4.11)*

<b>Sub-theme 4.11</b>
Recommendations or changes for support groups suggested by non-biological caregivers
<b>Categories</b> <ul style="list-style-type: none"> <li>• Suggestions that support groups should include information about HIV/Aids</li> <li>• Assistance in dealing with teenage pregnancy and the prevention thereof</li> <li>• Support groups need to be more accessible in communities</li> <li>• Having a purely emotional support group</li> <li>• Getting together again later</li> </ul>

Participants were asked to make suggestions on what they would change or recommend upon reflection of their support group experience. Five categories of suggestions were identified including support groups that should include information about HIV/ Aids, assisting caregivers in dealing with teenage pregnancies, for support groups to be more accessible in communities, having a purely emotional support group and getting together again later. These categories are discussed below:

A participant explained that she would have benefitted from information about HIV/Aids as some of her children are also affected by this virus. The researcher identified at least four participants who were looking after children affected by HIV/Aids in addition to prenatal alcohol exposure.

*-“Also **HIV/AIDS information** since some of the kids are positive...”*

Another suggestion was that the support group should assist caregivers in dealing with teenage pregnancies and the prevention thereof. This need could stem from the development of a secondary disability, namely inappropriate sexual behaviour, displayed by children with FASD (Streissguth, 2004).

*-“Educate the mothers to talk to their teenagers. They are at the age where they are gonna be pregnant so educate them. **Prevention of pregnancy to teenage girls** and caring for kids whose caregivers are still attending school. I am looking after little children whose mothers are still at school.”*

Two participants spoke about bringing the support group session closer to home. They requested that support groups be brought closer to townships so that it was more accessible. A participant explained



that the need for such services was great in her community and for her to attend her support group, high travelling costs were involved which not everyone could afford. She suggested that it be within walking distance:

*-“**Bring it home. Bring it more closer to home.** Because, you especially when you stay in a township like we were... I’m talking about my experience stay in a township... we do not have all of those things. People do not want to pay that R7, 50 to come to groups. They feel... you know... all... all rest stays in dire... unbelievable conditions... So, it’s just an effort for them to get up in the mornings... out of their dirty bed... out of their dirty house and then bath and get in a taxi to go there. **They want something that they can just... like walking distance.**”*

There was a further suggestion highlighting the need for another support group which purely focussed on emotional support for caregivers as caring for such children can be very draining. She suggested that such a group provide the opportunity in which there was more time for them to share with each other as opposed to learning about the disorder and focussing on specific session related topics.

*-“...Our support group was... there was a topic and that was what we were going for. And we... and in that we learnt a lot. So, it’s not that we didn’t, we learn a lot out that but it was for a specific topic. But you always **often felt that people wanted to share more and it’s more on the emotional side because living with an FASD child is so draining.** So, you want to share more in the experience of the child on the emotional side of it so that there... Hmm. So, and I’m not sure **if a support group if there might just be a totally different support group for that.**”*

Another participant was in agreement with the above suggestion, stating that she was disappointed that she was only given one opportunity to discuss her experiences related to the specific topic of that session and that she would have appreciated the opportunity to share more regarding her experiences of the week before:

*-“Um the only negative was that I would’ve wished it would be more um that, say they would **ask you in the week before coming here, what did you experience at home.** There was no chance to speak of your own personal things that happened in that week. It was always just related to the questions of the group of that day, Ja.”*

The last suggestion was the development of follow up group sessions in which the group members can come together so that they could see how they have changed and how the children are adapting into the new environment at home. The comment is given below:

*-“Sal weer lekker wees om **later op ‘n later stadium net weer saam te kom** en dit weer net te sien hoe mens... hoe ons verander en hoe het jou kinders ingepas.”*

*[It would be nice **to get together again at a later stage** with the group members to see how they... how we have changed and how the children have fit into this].*

## 4.5 CONCLUSION

Within this chapter the experiences of 16 caregivers of FASD children were investigated and it was determined that their experiences and utilisation of supports groups specifically aimed at this disorder was overall a very positive experience which helped them tremendously in changing their views on parenting FASD children and gaining new knowledge and support that could not have been provided elsewhere. It was found that there was a balance between an educational- and mutual aid approach in support groups. It was evident that there was a big need in communities for such a support group to be more accessible. Caregivers were empowered to be advocates and information sharers in their local communities, which they embraced and executed successfully. From the above findings it is clear that there is a large need for the provision of support groups for non-biological caregivers.

## CHAPTER 5

### CONCLUSIONS AND RECOMMENDATIONS

#### 5.1 INTRODUCTION

The aim of this chapter is to present the findings from the empirical study that was conducted about the experiences and utilisation of support groups by non-biological caregivers of FASD children. Recommendations that could potentially improve service rendering to non-biological caregivers will also be made with the aim of increased support to those affected. A final recommendation for further research will also be made that stemmed out of the findings of the previous chapter and as far as possible related to the findings and conclusions of this research study.

#### 5.2 CONCLUSIONS AND RECOMMENDATIONS

The following section will constitute the conclusions and recommendations made as a result of the findings yielded by the empirical study (see Chapter 4). The format that will be followed will be in accordance with the layout of Chapter 4. The Identifying details, the implications of FASD on children, the extent to which non-biological caregivers are affected and the utilisation and experiences of a support group will be concluded and followed by corresponding recommendations.

##### 5.2.1 Identifying details

This section will discuss the residential area, time period of the caregiving relationship to children and what the caregiver roles consist of.

#### Conclusions

- In terms of residential area, there was an even distribution of participants with half living in an informal settlement and the other half in a town or city. The misconception that only the poverty stricken communities and wine producing areas are impacted mainly by FASD can therefore not be assumed. Although it is not clear from which areas the affected children originate, the focus of the study was to determine where they currently reside.

- The majority of participants were foster caregivers which can be an indication that this form of alternative placement is mostly impacted by FASD.
- The majority of the caregivers have cared for their affected children for more than five years. A conclusion can be drawn that the placements could be successful as a result of support, although minimal, that the caregivers have received. Thus they have not experienced placement breakdown, which often results due to a lack of support and knowledge of FASD.

## Recommendations

- Researchers should not limit their studies to specific geographical areas as FASD impacts all caregivers in various parts of society.
- Structures should be put in place to create more awareness around FASD. This could highlight and inform prospective foster caregivers and other non-biological caregivers that children in the care systems might be affected with FASD and that they may come into contact with affected children.
- In order for placements to be successful in the long run, non-biological caregivers should be educated on FASD and provided with on-going support in the form of support groups and training opportunities on how to care for the children with FASD.

### 5.2.2 Implications of FASD

An investigation was undertaken to determine how non-biological caregivers can be impacted when finding out more about FASD once a child has been placed with them.

## Conclusions

None of the participants had prior knowledge of what FASD is although an affected child had been placed in their care. This may be because of the lack of overall acceptance of FASD in society.

- There was variety of emotions experienced as a result of learning more about the implications of FASD. Non-biological caregivers were not knowledgeable about what FASD was and how they would be affected in their caregiving role. Being faced with an unfamiliar challenge and becoming aware of the injustice towards the affected child, may have been overwhelming for

the participants. The majority of the emotions experienced were negative in nature, with only some participants seeing this new challenge as an opportunity for personal growth.

## Recommendations

- There should be more awareness created around FASD in the general population through various media channels, by hosting charity events and concerts in aid of FASD. Prospective non-biological caregivers should also be made aware that children in the care systems might be affected and could be placed with them.
- In order for foster parent screening to be successful, foster parent training should include aspects and implications of FASD, which could prepare non-biological caregivers emotionally in the event of discovering a child is affected. This may lessen the extent of the negative emotional impact on them.

### 5.2.3 The extent to which non-biological caregivers are affected by the consequences of FASD

#### 5.2.3.1 *Areas of challenge*

The following challenges were identified; gaining an appropriate educational environment for children, keeping the children involved in society, adapting households to meet the unique needs of FASD children, dealing with new and continual behavioural problems, sexual urges of FASD children and sudden aggressive outbursts. These will be discussed below.

## Conclusions

- Caregivers experienced difficulty procuring an adequate educational environment for their children and stated that the public schools did not understand FASD, and could therefore not provide their children with the required support. The conclusion can be drawn that the public school sector does not sufficiently provide for the unique needs of an FASD child and may still need to equip itself in order to accommodate children with FASD who do not fall on the severe disability scale.

- Children with FASD often experience difficulty staying involved in society possibly due to their associated social skills deficiency. Several participants were however able, with a teamwork approach, to keep their children involved in society.
- Caregivers explained that they were able to adapt their households more effectively possibly as a result of learning how this can be done at a support group. Another reason could be that many homes did not contain much content due to poorer living conditions as observed by the researcher or reported by participants.
- Caregivers in this study reported difficulty when attempting to deal with on-going behavioural problems, inappropriate sexual behaviour and sudden aggressive outbursts presented by their children. Such behaviours could be attributed to possibly brain damage associated with prenatal alcohol exposure that causes impaired functioning.

## Recommendations

- The public school system needs to investigate the need for additional support structures and resources targeted to address disabilities such as FASD if affected children are to be accommodated in government schools. The current structure of 'inclusive education' provides for children with mild intellectual and learning disabilities to be included within the mainstream system. However, it could be revised and implemented more efficiently so that children with FASD can also be supported whilst at public schools in the future. Each school should have professionals such as social workers, educational therapists and learning support teachers that function as a multi- disciplinary team that render support to the affected children. An additional investigation could be undertaken to expand on the amount of special needs schools, individual learning centres or skills schools that are effective in supporting FASD children and increase their capacity to accommodate more children in need.
- More awareness should be created in society to gain a better understanding of the difficulties experienced by an FASD individual. This could assist communities and community facility providers to be more accommodating to such children and their families.

- Support groups and training opportunities should continue to assist caregivers in adequately adapting their households in order to create an environment which children with FASD will find most supportive and beneficial.
- Caregivers should be trained to deal with the on-going challenges that they encounter daily. This training could take place in support group contexts or through other organised training facilities.

### **5.2.3.2 Implications due to FASD**

Nine implications were identified and will be discussed in the following section.

## **Conclusions**

- The majority of the participant's reported that they experienced emotional conflict possibly due to the continuous battles they face in providing care for their children. They describe a feeling of being forced to deal with their own challenges as well as with those of the child.
- Most of the participants experienced continuous setbacks as they were unable to anticipate the behaviour of their children. Foster caregivers had to continuously remind their children of daily activities that they forgot or struggled with, possibly due to their intellectual challenges. It can be concluded that the caregivers appeared to be challenged by the many associated factors which a FASD child often presents with.
- The indicated amount of caregivers who experienced high levels of stress was not met with the expectations of the researcher. This could be due to participant's perception of support that they had received. Support included aspects such as the friends made at the support group, information that they have gained and the special education their child currently receives. It can be concluded that even minimal support could assist in reducing the levels of stress experienced by caregivers.
- Participants were reportedly less exhausted than what was anticipated by the researcher. This could be because the majority of the participants were able to care for themselves and had access to some form of respite care. It can be concluded that caregivers often do not have

access to professional respite workers but that a family member or close friend was able to support them in taking time off to relax and so prevent exhaustion.

- There was overall agreement that caregivers with FASD children have limited support due to it possibly not yet being recognised as a major problem in society and therefore may explain the lack of support structures in place.
- The majority of the participants thought about the possibility of forever parenting as they have a good understanding of the daily struggles faced by their children in terms of independent functioning. Caregivers also had to accept that they would be required to support their children for much longer than originally anticipated. Fortunately, alternative placements and living opportunities are available such as supervised living for adults with disabilities, when caregivers are no longer able to assist affected individuals during adulthood.
- Some participants mentioned that they struggle to make and keep plans and that there is a need for babysitters, friends and family members who can stand in for caregivers when they have appointments to attend. If caregivers have a support structure around them, that understands the challenges of the FASD child, it may allow caregivers more freedom to make and follow through with their plans.
- Many participants experienced loss and grief as well as a fear and hopelessness when they thought of the future of their children. This is presumably because they are aware that there are limited opportunities and institutions that accommodate adults with FASD. Caregivers are also aware that their children may face various challenges trying to function in society and the possibility of developing of secondary disabilities is common.
- Participants' stated that they felt judged by others and were blamed for bad parenting. This is in all likelihood because the onlookers did not understand the challenges FASD children and their caregivers struggled with daily.



## Recommendations

- Caregivers of children with FASD should have access to emotional support, in a group context and be allowed to consult with professional people, who can assist them to deal with their conflicting emotions.
- Training opportunities should be provided to teach caregivers practical ways to help their children with daily tasks. This could help decrease the amount of stress associated with resulting continuous setbacks.
- Caregivers should continue to be supported by their available support structures addressing FASD. This may assist in decreasing experienced stress.
- Greater access to respite carers should be made available. This could be an avenue that should be explored by social welfare agencies who could train individuals to pursue this as a possible career. An additional recommendation would be to include friends and family in training opportunities, so that they can be better equipped in offering respite care for the children.
- Greater attention should be given to the development of alternative placement opportunities that will allow for a measure of independence but also assist FASD adults with their daily challenges.
- Caregivers should be supported and guided on how to best educate their friends, family and or babysitters regarding how to manage and care for an FASD child.
- Welfare organisations should be empowered to develop and maintain a support system for adults with FASD. Advocacy should take place that addresses their employment-, housing- and social needs which could facilitate the successful integration of affected individuals into society.
- It is recommended that the stigma attached to FASD be addressed and removed. A 'no-blame' attitude should be adopted and promoted in society, so as to create an understanding that alcohol consumption should be blamed for the challenges that affected children and families face and not the bad parenting of non-biological caregivers.

### 5.2.3.3 *Being able to access services to assist non-biological caregivers in caring for the FASD children*

Participants identified four categories of services that they have access to with regards to caring for FASD children. These categories are discussed below.

## Conclusions

- Firstly, participants did not mention a wide variety of medical services that were accessible apart from their local clinic that provided children with ARV medication and Ritalin, for those who have hyperactive behaviour. A conclusion can be made that most basic medical services are offered to children in non-biological placements and that FASD is not sufficiently addressed through medical services such occupational therapy, physiotherapy, speech therapy and psychology as recommended by health guidelines relating to FASD. There was an observed lack in the variety of medical assistance utilised by the participants. This is possibly caused by a lack of health professional awareness and their capacity to address the consequences of this disability.
- Secondly, participants who had been involved with welfare organisations that could assist in supporting them and their FASD child experienced a sense of relief. This could be due to access to professional support and advice which they can apply at home. It could also be as a result of the organisation being able to assist them to gain access to necessary resources, such as special needs schools and support social workers that can assist them in their homes.
- In the third category participants viewed religious institutions as an important support system as they show acceptance and are able to provide a safe environment where the children could be included and supported within a community.
- Lastly, all the participants who reported that they have access to specialised educational environments for their affected children, experienced a greater sense of relief and had renewed hope for their child. This was because they could see a great difference in the experience, development and well-being of the child. A conclusion can therefore be drawn that schools that recognise the unique needs of this developmental disorder are able to meet

the educational needs of these children and families through specialised and individualised interventions.

## **Recommendations**

- There should be an overall audit of the healthcare system in determining how they can improve their service rendering to children and families who are affected by FASD. Issues such as prevention, diagnosis and intervention services all fall within the health care system. Health care practitioners need to be formally trained to recognise FASD and to improve their capacity to confidently assist families in their struggles. A wider variety of services including, physiotherapy, occupational therapy, and psychologists should be made more readily available at local clinics to assist affected children.
- There appears to be a need for the national welfare system to recognise that FASD is a serious social issue in South Africa. Decisions should be made for all Non-Governmental Organisations and welfare agencies to undergo training in the nature (implications and strategies) of FASD so that effective service rendering can be offered to families that approach such organisations. The assistance offered should not be limited to a mere handful of organisations that do not have the capacity, or resources to support the vast amount of individuals affected.
- Religious institutions should continue to provide support to its members by meeting their unique needs where possible. This can be done by educating faith based social workers about FASD.
- Specialised educational systems that are already in place should be supported and strengthened so that their capacity to support more FASD children will be safeguarded. These schools may be beneficial as they could provide one-on-one learning environments that include life skills and vocational training in their curriculum. The educational approach of schools that specifically address FASD that have achieved success in the South African context should be acknowledged and given the opportunity to share their challenges and successes with other similar schools to increase the support base for children with this disorder.

#### **5.2.3.4 Social worker's understanding of FASD and the ability to render services to support non-biological caregivers**

Previous research (Kellerman, 2010:1) found that there is a lack of thorough knowledge amongst professionals connected to the child protection system regarding FASD. The result is ineffective service rendering to children and families entering the care system. The conclusions and recommendations resulting from the current study will now be discussed within four categories namely; a lack of understanding FASD, lack of contact and follow up, the turnover of support staff and the struggle to attain a social grant.

### **Conclusions**

- Many of the participants were of the opinion that social workers assigned to their case, were not well informed about the implications of FASD and had a lack of understanding regarding the impact it has on children and caregivers. Very few services addressing the challenges associated with this disability were rendered to them. This could be due to the possibility that many social workers may not be adequately trained and experienced in the field of FASD.
- A common finding observed was the lack of contact and follow up, once children were placed with caregivers. Factors such as heavy caseloads, limited time availability and too much focus on crisis management could be to blame and therefore be a reason why social workers are unable to follow prescribed guidelines of service rendering.
- Participants in the study shared that they struggled to build relationships with the social worker due to high turnover rates of staff. This made effective team work very difficult as they continuously dealt with different social workers which they found frustrating. This is presumably due to high staff turnover rates within welfare organisations and a lack of communication between the various role-players involved with the families at different stages of the support provision process.
- Participants voiced their struggle in securing foster care grants to assist them with caring for their children. This could be due to the confusion of the application process, the lengthy processing period and the lack of support that they received from local social service agencies.

## Recommendations

- It is strongly recommended that FASD be made more of a priority in the social welfare system so that adequate training can be provided to support staff in order for better services to be rendered. It is also recommended that training institutions place more focus on this issue so that professionals could apply suitable strategies and be more successful in their field of work.
- Effective methods such as training opportunities and group work should be used in which more than one individual can be supported and assisted at a given time. Community workers could also be identified and trained in the field of FASD to make home visits and offer support to affected families.
- It is recommended that clear communication channels be created between staff members so that repetition of work is prevented ensuring families are supported effectively. Social workers would benefit from improved working conditions and support as a means to decrease the high rate of staff turnover.
- It is recommended that caregivers receive useful and understandable direction from support staff during the grant application process and the current processing system should be reviewed and improved to ensure that it is more effective in service rendering.

### ***5.2.3.5 Other children and family members in the household being affected***

Participants explained how their own biological children and other family members were affected by the FASD child. The conclusions and recommendations drawn from these findings will be introduced and discussed below.

## Conclusions

- Firstly, the reported finding was that biological children were affected differently. Some children were negatively impacted by FASD children in the household. This could be because children in the same household were being parented differently to the affected children or because the affected children received more attention. There were also positive results. This may have been as a result of older children spending quality time with the FASD children and possibly acting as role models to them. They also had peace of mind that their parents were

not alone in the home anymore. And lastly, that older children could provide materialistically for the caregivers.

- Secondly, participants shared that their spouses and own parents were affected by the FASD children. This can be attributed to not understanding the disorder completely and not being able to relate to the challenges that the primary caregivers experience in caring for the affected child.

## Recommendations

- The biological children of caregivers should be active participants in the caregiving process and must be acknowledged for the role they play. It is thus recommended that they be provided with support structures such as a support group in which they have an environment to learn more about the disability and have the opportunity to share their personal experiences.
- Other family members such as spouses and caregivers of the non-biological caregivers should also be involved in the training opportunities and support group sessions to ensure that they understand the implications of FASD better and are able to provide support to the primary caregivers.

### ***5.2.3.6 The understanding of FASD by extended family members and friends and their ability to support non-biological caregivers***

## Conclusions

- It can be concluded from the findings of this study that the extended family and friends do not always understand FASD and as a result may not be able to support the caregivers in their roles. This stems from the participant reports that the offered help from family was not effective and often counterproductive for the children. In the instances where participants reportedly managed to teach their friends and family some important aspects regarding FASD, they remained in denial and thought that it would end soon. This may be caused by a lack of understanding that FASD is a lifelong disability. Furthermore, many children may not present obvious physical features associated with FASD and are consequently treated in the same as other children in the household.

## Recommendations

- It is recommended that extended family and friends be included in information sessions or that the caregivers attending support groups be provided with an information leaflet which could be distributed to their loved ones in order to assist in creating an awareness and understanding of FASD.

### 5.2.4 The utilisation and experiences of a support group

#### 5.2.4.1 *The need for support in caring for children affected by FASD*

## Conclusions

- All the participants agreed that there is a big need for support possibly because dealing with a FASD child was a foreign concept to them. Participants also mentioned that they were overwhelmed by what was required from them when caring for an FASD child. It can thus be concluded that support may be crucial to non-biological caregivers and others, whether they are a professional or not. This could help them understand and allow them to relate to what the participants are experiencing.

## Recommendations

- It is recommended that there should be an increase in the amount and type of support available to non-biological caregivers. This is not merely in the form of support groups but in all related spheres and role players that they may come into contact with. In order for this to be achieved national recognition of FASD should take place so that it filtrates through to service rendering.

#### 5.2.4.2 *Support groups playing a vital role in supporting non-biological caregivers*

Caregivers felt that support groups were a vital source of support to them. Three reasons were provided as to why they thought it was important to them namely, the provision of emotional and educational support, understanding the child better and ineffective support groups.

## Conclusions

- Participants in this study felt that support groups play a vital role in supporting them as they had experienced a gain in many emotional and educational aspects. This could be due to the designed nature of the support groups attended which attempted to provide its' members with factual information as well as an opportunity for emotional growth.
- Non-biological caregivers benefitted from the support group because it enabled them to understand their affected children better. The conclusion can be made that support groups, such as presented in the current study, educate caregivers about the struggles their children face as a result of FASD, thus helping them improve their understanding.
- Participants of this study voiced that they had attended foster caregiver support groups that were not as effective in supporting them. This is possibly because those support groups may not have been structured to meet the immediate needs of attendees and especially around FASD.

## Recommendations

- It is recommended that future support groups maintain and promote a balance between educational and emotional aspects surrounding FASD as achieved in this study.
- It is recommended that support groups should always ensure that they assist caregivers by allowing them to share misconceptions and providing them with information that could allow for improved understanding.
- It is recommended that the organisers of support groups utilise their introductory sessions to determine what the needs of caregivers are, as this may ensure that they address all possible avenues and needs of the participants.

### 5.2.4.3 *Ways in which support groups help non-biological caregivers cope better*

## Conclusions

- Participants stated that they were equipped to cope better because they were empowered through an environment that assisted them, to think differently about their circumstances by



relating to others in a similar situation. Caregivers also felt relief in knowing that others were either in the same or in a worse situation than them. This is possible because they then realise that they will be fine if others can manage to get through worse situations, then so can they. It can therefore be concluded that a support group enables caregivers to cope better with their own daily struggles.

## Recommendations

- It is recommended that support groups in the work with FASD need more attention so that caregivers are enabled to cope better by creating a safe and trusting environment in which caregivers can share and relate to each other's situations.

### 5.2.4.4 *Meeting the group member's expectations about the group sessions*

## Conclusions

- Within this study it was evident that the majority of the group member's expectations were met. This could be due to gaining a better understanding of their children and FASD. One participant stated that she had no expectations but that she still felt that she had benefitted from the group sessions. It can be concluded that it is important to ask group members in the formation phase what their expectations are so that both the hosting party and participants are aware of this.

## Recommendations

- It is recommended that the organisers of the support group remember to ask the group members what their expectations are in order to ensure that they met or changed in line with what the support group aims to achieve. This may prevent unnecessary dissatisfaction.

### 5.2.4.5 *Emotional support in the support group context*

Four categories were identified when looking at how non-biological caregivers can receive emotional support in a support group context. Each of the four categories will be discussed below.

## Conclusions

- The majority of the participants indicated that they experienced respect and non-judgmentalism from the other group members. This could be attributed to the possibility that caregivers regard each other as equals and understand that their caregiving circumstances are the determining factor for attending the support group. Members explained that the respect and non-judgmentalism they received in their community was not perceived in the same way and they were often scrutinised for taking care of the foster children. This is probably because the community has a different understanding of their role in caring for children not belonging to their own family.
- Caregivers participating in this study reported that they experienced shared relationships with the other members of the support group. This could be owing to the realisation that they are not the only ones caught up in an extraordinary situation that no one else can understand.
- It was found that all of the participants experienced normalisation. This could be attributed to caregivers understanding that they are not responsible for the challenges they are facing and that their situation was caused by the preceding behaviour of the child as a result of their disability.
- All of the participants felt that they made significant emotional progress. This could be as a result of the support group context which enabled the caregivers to train themselves to approach situations from different angles, to control their behaviour and to focus on the positive aspects and small success stories.

## Recommendations

- The support group environment should maintain a culture of respect in which participants do not feel judged because of their circumstances or situation. Community awareness programmes ought to include the importance of foster care. These programmes should allow for non-biological caregivers to be supported in their vital role instead of scrutinised by their local communities.

- Support groups should ensure that the message is always carried across and that their fellow members and professional facilitators understand that their situation may seem extraordinary at times nonetheless they are not alone in their experiences.
- Facilitators of support groups should ensure that attendees do not adopt an attitude of self-blame for their stressful situations, but instead assist them in identifying how the disability is contributing to the challenges, and then look at how this can be addressed effectively.
- An understanding and loyal working environment should be purposefully created before group members will truly open up emotionally and look at approaching their unique situations from different angles.

#### **5.2.4.6 Practical support in the support group context**

Six categories were identified when looking at how non-biological caregivers can receive practical support in a support group context. Each of the six categories will be discussed below;

### **Conclusions**

- Firstly, all of the non-biological caregivers indicated that they were able to change their thought patterns regarding FASD. This may be attributed to the reported change in how they viewed the child's behaviour as being deliberate to behaviour being out of their control.
- Secondly, all of the participants agreed that they had an opportunity to rest when they attended the support groups. This is possibly because participants were given a rest from looking after their children, getting a break from their daily routines, being in the company of adults in a similar situation and receiving spiritual input.
- Thirdly, the opportunity to link with resources was viewed differently by participants. The majority of the group members looked to the individuals within the support groups as their main source of information as opposed to two participants, who already had more experience. These two participants stated that they gained no additional resources within the support group but instead gained further insight through their own efforts. This finding could be attributed to caregivers with fewer resources re-focusing their attention to their peers in order substitute for the lack of resources outside a support group context.

- Fourthly, there were also mixed opinions about the opportunity to advocate for FASD. The majority of participants residing in informal settlements, with less available resources, saw advocacy as educating their fellow community members by talking and through simple one-on-one information sharing opportunities. They were thus under the opinion that they did advocate to others. For more empowered individuals, advocacy was seen as bigger organised events. This finding could be attributed to the differing views of group members regarding what advocacy could include.
- Fifthly, the majority of participants felt that innovation and training took place amongst the group members. This could be as a result of group members teaching each other by exchanging their experiences and knowledge regarding the disability, skills to help deal with behaviour challenges and strategies for coping better.
- Lastly, all of the participants felt that they received practical tools from attending the support group. This could be attributed to caregivers reporting that they implemented the various tools that were provided by the support group and that it helped them successfully change their home environment.

## Recommendations

- Careful consideration should be given to how caregivers are educated on the behavioural problems children with FASD face as a result of the disability and not their freewill. Caregivers can be easily overwhelmed and information sharing should clearly state what the possibilities are, but also empower caregivers on how to address behavioural challenges.
- Group facilitators should try and create the most peaceful environment possible which will add to the feeling of rest. Little gestures such as encouraging notes, tea and snacks, praying together can also be incorporated into group sessions to encourage participants to relax and feel appreciated during the sessions.
- A resource directory should be created for group members, listing all the possible resources that can be utilised or approached to help caregivers care for their FASD children. If there is a lack of resources in the local community a list of internet websites that can be accessed for support, might also be effective in empowering participants.

- Group members should be supported in advocacy attempts. Professionals advocating with or for affected families can make a significant difference. Advocating opportunities in which caregivers and professional individuals can be involved in include information days, training opportunities and awareness campaigns in their local communities.
- Group facilitators should facilitate discussions between group members in order to ensure that innovation and training take place. When stagnation or deviation takes place the facilitator can intervene and keep conversation relevant to the particular topic.
- Facilitators should ensure that practical tools are provided in homework form, which will encourage members to implement it at home and provide feedback regarding the success thereof, at the following session.

#### **5.2.4.7 Approaches in support groups**

Within this section the researcher will discuss whether both the educational- and mutual aid approach in group work is effective in supporting caregivers.

### **Conclusions**

- All of the participants indicated that the support group helped them utilise their strengths. This may be attributed to the group facilitators helping participants focus on themselves in order to identify what they were good at, after which the other participants would affirm this.
- All participants reported that they felt like they were part of a community. This could presumably be caused by the development of a supportive and safe environment through the sharing of experiences.
- All of the caregivers explained that they were taught purposeful use of self through the process of sharing experiences and establishing better alternatives. A prominent change was that caregivers learnt to control their temper and not scream at the children as often. This is possibly due to realising that screaming at the child was not helpful and that calmer methods of discipline would be more effective.

- Participants reported that they felt like they had something worthwhile to offer to the group. This may be a result of participants identifying their personal strengths and seeing how their peers could benefit from it.
- Participants of this study indicated that they were able to talk and listen to their fellow group members. One participant added that she initially felt uncomfortable but that it became easier to talk as the sessions continued. This may be due to some participants being shy and withdrawn by nature, and so needing time to begin to trust other individuals before opening up.
- The majority of the participants indicated that they discussed taboos in their groups such as the inappropriate sexual behaviour of children, discipline methods used and why their children steal. They presumably saw these topics as taboo as they would not consider discussing these topics with community members who would not understand FASD children.
- The researcher can conclude that all of the participants felt like they were in 'the same boat' as their fellow group members. This may be attributed to participants realising that their situation was not as unique as they thought, and that they experienced the same challenges of FASD regardless of where they were residing.
- All of the participants reported that they were helped in facing difficult situations and coming up with new strategies and viewpoints. This could have been as a result of the creation of a conducive environment in which members were able to face and deal with situations they previously might not have been ready for. One group member indicated that she experienced it difficult at times, which could be attributed to the fact that individuals are not always ready to face their challenges.
- It can be concluded that there was overall group member agreement that they were able to problem solve better as an individual. This may be a result of participants being encouraged to go home and implement their newly gained knowledge and strategies where there were no members to support them practically.
- All of the participants indicated that they experienced role play within their group and that it was an effective way of learning. One participant indicated that even though she participated,

she did not enjoy it. This is presumably due to the some individuals finding such an activity intimidating and difficult.

- The researcher found that all of the participants *gained a better insight and understanding of FASD*. This may be attributed to the participants being able to gain first-hand experience from each other and further benefit from well-planned sessions with professional facilitators and guest speakers.
- It was observed that all participants of this study felt that they were provided *with relevant information that they could apply in caring for FASD children*. This resulted from participants making the newly gained knowledge part of their daily functioning and adapting themselves in such a manner as to improve their caregiving abilities.

## Recommendations

- It is the responsibility of the social work profession to identify and help build on the strengths of individuals and families. The support group could be the ideal place to do so and should be done.
- The facilitator of the group should employ strategies to develop a supportive and safe environment where participants would feel free to share their experiences thus creating an opportunity for a community to develop.
- Facilitators can lead a discussion that may result in the identification of counter-productive caregiver behaviours and possibly help participants identify more appropriate behaviours to support the FASD child.
- Activities aimed at helping members identify what they have to offer the rest of the group should be utilised in order to help participants take ownership of the group process.
- The facilitator should be aware of the communication process taking place in each of the group sessions. Members should be encouraged to participate even if they are initially quiet. The facilitator must also ensure that there is equal opportunity for all members to raise their opinions and prevent certain members from dominating the group.

- The opportunity to discuss taboo subjects should be raised deliberately and tactfully so that members are able to see that those challenges they are most embarrassed about are often as a result of the characteristics of FASD and not a reflection of their parenting skills.
- The facilitator should help participants see that they are in the same boat even if their situations are unique. Facilitators can ensure that participants have the opportunity to relate to each other through carefully planned discussion topics surrounding caregiver experiences.
- Participants who are not ready to face difficult situations should be supported by the facilitator and their peers but also held accountable and be encouraged to face these situations at some point in the near future. This could allow for new coping strategies to be developed.
- The facilitator should ensure that there is a supportive and energetic environment in which caregivers can be confronted regarding their behaviour, and as a means of learning new problem solving skills. They should then encourage members to go and implement the newly gained knowledge at home.
- Role play should be actively used in group sessions in order to allow participants to see various problems from different angles and also be involved in an active learning process. Participants who are not comfortable with this should be supported to do the best they can.
- Facilitators should refrain from only giving second-hand literature knowledge and allow for enough time in which caregivers with first-hand knowledge can share their understanding and experiences of FASD with each other.
- Facilitators should 'check-in' with participants in order to determine whether they perceive their newly gained insight as practical and implementable.

#### **5.2.4.8 *Positive aspects within a support group***

It can be concluded that participants experienced some of the following positive aspects within their support group environment. These aspects are listed and discussed below:

- Increased understanding of FASD
- Helping to care better for FASD children
- Gaining and employing new strategies



- Sharing experiences
- Finding mutuality
- Using humour
- Inspiration to hope
- Mentorship relationships

It was found that all the participants experienced all of the above mentioned positive aspects within a support group context. *Praying together* and *friendship* was also added to the list of aspects. The researcher will highlight three important findings that were reported during the investigation.

## Conclusions

- Firstly, participants reported that their traditional views about what this disability entails and how it is caused has changed. For many participants, individuals struggling with FASD were initially seen as being influenced by evil spirits or described as just being stupid. The change in viewpoint could be due to acquisition of new knowledge about the physical features of FASD, how it is caused and how it influenced the affected individuals' behaviour.
- Secondly, all of the participants were inspired to hope again. This was presumably caused by Participants hearing about the successes of others and by receiving unconditional support.
- Thirdly, all participants felt that mentorship relationships had formed over time. This may be attributed to the reports of participants that they had the opportunity to listen to each other and to the professional individuals with expert knowledge, who were responsible for guiding the group sessions.

## Recommendations

- Facilitators should be aware of and accommodate alternative views of the disability but also be tactful and respectful in helping participants understand the underlying medical reasons for this disability.
- The facilitator should deliberately provide the opportunity for caregivers to share their success stories with each other which will allow for members to experience a new sense of hope.
- The facilitator of the group should make arrangements with relevant professionals or FASD sufferers who could visit the support group when it is applicable, allowing them to share their experiences and expertise.

### ***5.2.4.9 Negative aspects within a support group***

Participants shared some of the following negative aspects within their support group environment. These aspects are listed and discussed below.

- One-size-fits-all mentality of participants
- Disappointment in the group process
- Anticipation of future challenges
- Friction between participants
- Jealousy over the well-being of other participants

## Conclusions

- Most of the negative aspects were never experienced within the support group. One aspect that was experienced more often than others was the *anticipation of future challenges*. The majority of the participants experienced this aspect presumably due to listening to the challenging stories of caregivers with older children and then realising that they were likely to face the same challenges, when their children grew older.

## Recommendations

- During discussions about challenges, caregivers shared personal experiences. From these discussions facilitators should learn and be able to identify when fellow participants show fear for the future challenges they may face. Participants should then be reminded that strategies could be put into place that can assist them.

### 5.2.4.10 *Recommendations or changes for support groups suggested by non-biological caregivers*

## Conclusions

- The suggestion was made that support groups should include information about HIV/Aids. This could be as a result of some of the participants looking after children who are affected by this disease as well and that they viewed the support group as a provider of relevant and helpful information.
- Another suggestion was made that participants should be assisted in dealing with teenage pregnancy and the prevention thereof. This may be attributed to some of the caregivers who reported caring for teenagers who are prone to sexual experimentation.
- Participants suggested that support groups need to be more accessible in communities. This is possibly due to the high travelling costs which not everyone in need of support can afford.
- A further suggestion was made that a support group with a purely emotional approach be offered. This might be as a result of the attended support group being more educational in nature and now that the participant has gained the educational knowledge there is still a need for more opportunities to discuss experiences and emotional challenges.
- A last suggestion for participants to get together again at a later stage was made. This is possibly due to the reported desire of participants to see how their peers have changed and how the children are adapting in their newly adapted home environments.

## Recommendations

- A more general information session can be held with caregivers, resulting from consultation with them regarding their needs, where issues such as HIV/Aids can be discussed. A more general parenting support group would also be able to include such in its layout.
- Discussing teenage pregnancies and the prevention thereof should be discussed in depth when the secondary disabilities of FASD are discussed or when the group looks at topics such as teenagers with FASD. A tip sheet should be handed out as a reminder that can be taken home. Caregivers with FASD children should also be advised to assist their children in the use of contraceptives as soon as they reach puberty.
- Support groups should be branched out into communities where it is needed. The use of a community leader or community worker should be considered as a mediator between the organisations and people, thereby offering the training to the prospective group members.
- A different form of support group could be offered after caregivers have completed a support group that is more informative and educational in nature. Such a group can provide for on-going emotional support amongst the participants.
- It is recommended that more informal group sessions be arranged between members at a later stage after their initial support group has finished, where they can meet informally and see how their peers are doing. A reunion can also be organised for old participants to come together and celebrate their successes.

## 5.3 RECOMMENDATIONS FOR FUTURE RESEARCH

Based on the findings from this study various recommendations for further studies can be made.

- It is recommended that further research be conducted into the ability of social welfare organisations to render co-ordinated and effective services to non-biological caregivers and children affected by FASD.
- Further research is needed on determining how siblings of FASD children are affected and can be supported successfully.

- Further research needs to be conducted to determine how government schools can be better equipped to deal with the unique needs of FASD children in order to give them alternative choices of study as to try and increase their chances of success in the future.
- Further research can be conducted to determine the effectiveness of solely emotional support groups where caregivers come together more informally to support each other.

## **5.4 FINAL CONCLUSION**

The identified goal of gaining an understanding about the experiences of non-biological caregivers of children with FASD and of the utilisation of support groups to help them cope better was achieved. This was enabled by explaining the implications of FASD on children and specifically highlighting the extent to which non-biological caregivers are affected by the consequences of this disability. The mutual aid- and educational approach underpinning support groups were clearly discussed and showed to be effective in supporting non-biological caregivers. The utilisation of support groups by participants of this study was then successfully investigated and information regarding the experiences of support groups in a South African context has been provided. Most of the data collected correlated with International research with a few exceptions such as the traditional views of disease and disability of the participants. It is clear from the study that there is a big need for recognition of FASD as a social issue in South Africa and the service rendering needs to be more targeted at helping non-biological caregivers be prepared and supported in their role of supporting and caring for children that are affected. It was clear from this study that support groups are effectively utilised by non-biological caregivers who have access to them and that they play an important role in providing support.

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**STELLENBOSCH UNIVERSITY**

**CONSENT TO PARTICIPATE IN RESEARCH**

---

**THE UTILISATION OF SUPPORT GROUPS FOR NON-BIOLOGICAL CAREGIVERS OF CHILDREN WITH FASD.**

You are asked to participate in a research study conducted by Bianca Breytenbach (Masters in Social work), a student from the Social work Department at Stellenbosch University. The results of this paper will become part of a research report. You were selected as a possible participant in this study because you are a non-biological caregiver of a child with Feta Alcohol Spectrum Disorder (FASD).

**1. PURPOSE OF THE STUDY**

The aim of the study is to gain an understanding on the experiences of non-biological caregivers of children with FASD of their utilisation of support groups.

**2. PROCEDURES**

- If you volunteer to participate in this study, we would ask you to do the following things:
- A semi-structured one-on-one interview will be utilized to gather information confidentially. Audio recording will be made during interviews for data analyzing purposes.
- The duration of the interview will be determined in relation to what is comfortable for you as participant and will be undertaken at a location you are most comfortable at.
- Confidentiality is of utmost importance and you need not indicate your name or any particulars on the interview schedule. The schedule will be completed during an interview conducted by the student-researcher.

### **3. POTENTIAL RISKS AND DISCOMFORTS**

Any uncertainties on any of the aspects of the schedule you may experience during the interviews can be discussed and clarified at any time. You will not be placed in a situation that is confrontational or threatening.

### **4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

With this study it is hoped that the social work profession will be provided with information regarding the utilisation of support groups for non-biological caregivers of children with FASD and where this profession can make positive contributions in the future.

### **5. PAYMENT FOR PARTICIPATION**

No payment in any form will be received for participating in this study.

### **6. CONFIDENTIALITY**

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of coding where each questionnaire is numbered. All questionnaires will be managed, analysed and processed by the student researcher and will be kept in a safe place. The provided information will later be published but anonymity is guaranteed.

### **7. PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

### **8. IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about the research, please feel free to contact:

Prof L Engelbrecht (Supervisor), Department of Social work, University of Stellenbosch,

Tel: 021- 808 2073, Email: [lke@sun.ac.za](mailto:lke@sun.ac.za)

### **9. RIGHTS OF RESEARCH SUBJECTS**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights

as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

**SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE**

The information above was described to me by Bianca Breytenbach in English and I am in command of this language or it was satisfactorily translated to me. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study.

I have been given a copy of this form.

\_\_\_\_\_  
**Name of Participant**

\_\_\_\_\_  
**Signature of Participant**

\_\_\_\_\_  
**Date**

**SIGNATURE OF INVESTIGATOR**

I declare that I explained the information given in this document to \_\_\_\_\_ [name of participant] [He/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in English and no translator was used.

\_\_\_\_\_  
**Signature of Investigator**

\_\_\_\_\_  
**Date**

## ANNEXURE B



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### UNIVERSITEIT VAN STELLENBOSCH

#### BEREIDWILLING OM DEEL TE NEEM AAN NAVORSING

---

#### **DIE GEBRUIKMAKING VAN ONDERSTEUNINGSGROEPE DEUR NIE-BIOLOGIESE VERSORGERS VIR KINDERS MET FASD.**

U word gevra om deel te neem aan 'n navorsingstudie, wat uitgevoer word deur Bianca Breytenbach (Meesters in Maatsklike Werk), 'n student van die Maatskaplike Werk Departement, Universiteit van Stellenbosch. Die resultate van hierdie studie sal deel vorm van 'n navorsingstesis. U is as deelnemer in die studie gekies omdat u voldoen aan die navorsingskriteria, naamlik, dat u 'n versorger is van 'n kind met FASD.

#### **1. DOEL VAN DIE STUDIE**

Die doel van die studie is om 'n begrip te ontwikkel oor die ondervinding van nie-biologiese versorgers van kinders met FASD en hul gebruikmaking van ondersteuningsgroepe.

#### **2. PROSEDURES**

- Indien u bereidwillig is om aan die studie deel te neem, vra ons dat u sal instem tot die volgende:
- 'n Semi-gestruktureerde een-tot-een onderhoud sal gebruik word om inligting vertroulik te versamel. Klank opname sal gemaak word gedurende die onderhoud vir die doel van data analise.
- Die duur van die onderhoud sal vasgestel word in verband met wat gemaklik vir u as deelnemer is en sal onderneem word by 'n plek waar u gemaklik voel.
- Vertroulikheid is van notale belang en u naam en geen persoonlike informasie sal gedurende hierdie onderhoudskedule aangedui word nie. Die skedule sal deur die student-navorser voltooi word gedurende die onderhoud.

### **3. MOONTLIKE RISIKO'S EN ONGEMAK**

Enige onsekerhede wat u ervaar oor die aspekte van die skedule gedurende die onderhoud kan enigetyd met die student-navorsers bespreek en uitgeklaar word. U sal nie in 'n situasie geplaas word wat u konfronteer of bedreig nie.

### **4. MOONTLIKE VOORDELE VIR DIE DEELNEMERS EN/OF DIE SAMELEWING**

Met hierdie studie word gehoop dat die maatskaplike werk professioneel voorsien sal word met informasie in verband met die gebruikmaking van ondersteuningsgroepe deur nie-biologiese versorgers van kinders met FASD en waar hierdie professionele 'n positiewe bydrae kan maak in die toekoms.

### **5. VERGOEDING VIR DEELNAME**

Geen geldelike vergoeding sal deur deelnemers van hierdie studie ontvang word nie.

### **6. VERTROULIKHEID**

Enige inligting wat deur hierdie navorsingstudie ingesamel word, sal vertroulik bly en slegs met u toestemming bekend gemaak word of soos die wet dit vereis. Anonimiteit sal bereik word deur middel van 'n koderingstelsel waar elke vraelys genummer sal word. Alle vraelyste sal deur die student-navorsers bestuur, geanaliseer, verwerk en veilig gestoor word. Die resultate van hierdie studie sal gepubliseer word, maar anonimiteit van deelnemers word gewaarborg.

### **7. DEELNAME EN ONTTREKING**

U kan self besluit of u aan die studie wil deelneem of nie. Indien u inwillig om aan die studie deel te neem, kan u enige tyd onttrek sonder enige nadelige gevolge. U kan ook weier om op bepaalde vrae te beantwoord, maar steeds aan die studie deelneem. Die ondersoeker kan u aan die studie onttrek indien omstandighede dit noodsaaklik maak.

### **8. IDENTIFIKASIE VAN ONDERSOEKERS**

Indien u enige vrae of bekommernis omtrent die navorsing het, tree asseblief vrylik in verbinding met:

Prof L Engelbrecht (Supervisor), Departement van Maatskaplike Werk, Universiteit van Stellenbosch.

Tel: 021- 808 2073, Epos: [lke@sun.ac.za](mailto:lke@sun.ac.za)

### **9. REGTE VAN DEELNEMERS**

U mag op enige tydstip u onttrek en u deelname beëindig, sonder enige nadelige gevolge. Deur deel te neem aan hierdie studie doen u geensins afstand van enige wetlike regte, eise of regsmiddels nie. Indien u vrae het oor u regte as

deelnemer, skakel Me Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] van die Afdeling Navorsingontwikkeling, Universiteit van Stellenbosch.

**VERKLARING DEUR PROEFPERSOON OF SY/ HAAR REGSVERTREENWOORDIGER**

Die bostaande inligting was aan my verduidelik deur Bianca Breytenbach in Afrikaans en ek is dié taal magtig of dit was bevredigend aan my vertaal. Ek was die geleentheid gebied om vrae te stel en my vrae is bevredigend beantwoord.

Ek stem hiermee vrywillig in om deel te neem aan die studie.

‘n Afskrif van hierdie vorm is aan my gegee.

\_\_\_\_\_

**Naam van deelnemer**

\_\_\_\_\_

**Handtekening van deelnemer**

\_\_\_\_\_

**Datum**

**VERKLARING DEUR ONDERSOEKER**

Ek verklaar hiermee dat ek die inligting in hierdie dokument vervat, verduidelik het aan \_\_\_\_\_ (naam van deelnemer). Hy/sy is aangemoedig en oorgenoeg tyd gegee om vrae aan my te stel. Dié gesprek was in Afrikaans gevoer en geen vertaler was gebruik nie.

\_\_\_\_\_

**Handtekening van onderzoeker**

\_\_\_\_\_

**Datum**

**ANNEXURE C**

**SEMI STRUCTURED QUESTIONNAIRE**  
**UNIVERSITY OF STELLENBOSCH**  
**DEPARTMENT OF SOCIAL WORK**  
**INTERVIEW SCHEDULE**

**THE UTILISATION OF SUPPORT GROUPS FOR NON-BIOLOGICAL CAREGIVERS OF CHILDREN WITH FASD**

**All the information recorded in this interview will be regarded as confidential. The views and personal information provided by the respondents will be kept anonymous. Please answer the questions as open and honest as possible.**

**1 IDENTIFYING DETAILS**

1.1 Where do you reside?

Informal Settlement	
Town or City	
Farm	
Other: _____	

1.2 How long have you been involved in a non-biological care giving role to the FASD child/ren?

Number of children	Period of time

1.3 What is your relationship to the child/ren?

	Relationship	Number of Children
Adoptive Parent		
Foster Parent		
Grand Parent		
Other Extended Family		
Respite Care		
Other: _____		



## 2 IMPLICATIONS OF FASD ON CHILD/ REN

2.1 Did you know anything about FASD before the child/ren came into your care?

Yes	No
-----	----

If yes, what did you know

.....

2.2 How did that make you feel to find out that the child/ren is affected by FASD?

Anger	
Anxiety	
Denial	
Fearful	
Frustration	
Grief	
Helpless	
Other: _____	

## 3 EXTENT TO WHICH NON-BIOLOGICAL CAREGIVERS ARE AFFECTED BY THE CONSEQUENCES OF FASD

3.1 Do you face challenges in one or more of the following areas?

	Yes	No
Gaining educational environment for child		
Keeping the child involved in society		
Adapting your household to meet the unique needs of the FASD child/ ren		
Dealing with new and continuous behavioural problems		
Other: _____		

Additional comments: .....

## 3.2 Do you experience the following implications?

	Yes	No
Emotional Conflict		
Continuous Setbacks		
High Levels of Stress		
Exhaustion		
Are you able to care for yourself?		
Do you have access to respite care?		
Do you battle for support?		
Thinking about the possibility of forever parenting?		
Do you feel unappreciated and taken for granted?		
Are you able to make and keep plans?		
Have you experienced loss/ grief with regards to the children's future?		
Do you experience fear and hopelessness for the future of the children?		
Do you feel judged by others?		
Other: _____		

Additional comments: .....

3.3 Are you able to access services to assist you in caring for the FASD children? (Medical, educational and social). Please motivate.

.....

3.4 Does the Social worker assigned to the affected children understand the condition and is he/she able to render services to support you as caregiver? Please motivate.

.....

3.5 How are other children and/or other family members in the household affected by the FASD child? Please motivate.

.....

3.6 Does your extended family and friends understand FASD and are they able to support you in your role as non-biological caregiver?

.....

#### 4 THE UTILISATION AND EXPERIENCES OF A SUPPORT GROUP.

4.1 Do you need support in caring for the FASD children? Please explain.

.....

4.2 Do you feel that support groups play a vital role in supporting non-biological caregivers of FASD Children? Why?

.....

4.3 How many group sessions have you attended? \_\_\_\_\_

4.4 How did the support group help you with your ability to cope better as a caregiver?

.....

4.5 Were your expectations about the group sessions met? Please explain

.....

4.6. Have you experienced the following forms of emotional support in the support group context?

4.6.1 Absolute Respect and non-judgmentalism by your group peers.

Yes	No
-----	----

Please Explain

.....

4.6.2 Common/ shared/ reciprocal relations to other non-biological caregivers.

Yes	No
-----	----

Please Explain

.....

4.6.3 Normalisation of your circumstances/ situation (it feels more normal).

Yes	No
-----	----

Please Explain

.....

4.6.4 Enablement of significant emotional progress.

Yes	No
-----	----

Please Explain

.....

4.7. Have you experienced the following forms of practical support in the support group context?

4.7.1 Enabling you to change your thought patterns regarding FASD.

Yes	No
-----	----

Please Explain

.....

4.7.2 An opportunity for respite/ rest.

Yes	No
-----	----

Please Explain

.....

4.7.3 Linking with resources within the group.

Yes	No
-----	----

Please Explain

.....

4.7.4 Were you able to advocate within the group context? (Bigger efforts such as awareness days, conferences, research studies and media projects).

Yes	No
-----	----

Please Explain .....

4.7.5 Innovation/ improvement and training between group members.

Yes	No
-----	----

Please Explain .....

4.7.6 Did you receive practical tools (such as schedules, routines, charts, ideas?)

Yes	No
-----	----

Please Explain .....

4.8 Approaches in support groups

4.8.1 Did the support group assist you in using your strengths as caregivers?

.....

4.8.2 Did you feel like part of a community in the support group?

.....

4.8.3 Did the group work sessions teach you purposeful use of self? (How to take control of your behaviour).

.....

4.8.4 Do you feel like you had something worthwhile to offer the group?

.....

4.8.5 Where you able to talk and listen to your fellow group members?  
.....

4.8.6 Where there ever Taboos/usually forbidden topics discussed in your group? (Example-disciplining techniques). Please give me an example.  
.....

4.8.7 Do you feel like others are in “the same boat as you” after joining the group?  
.....

4.8.8 Where there situations where the support group helped you face difficult situations and help come up with new viewpoints or strategies?  
.....

4.8.9 Are you now able to problem solve better as an individual?  
.....

4.8.10 Where there situations that rehearsal/ role play took place?

Yes	No
-----	----

4.8.11 Do you feel that you have gained better insight and understanding of FASD after attending a support group?  
.....

4.8.12 Where you provided with relevant information that you could apply in caring for the affected child?  
.....

4.9 Did you experience some of the following positive aspects within the support group?

	Yes	No
Increased understanding of FASD		
Helping you care better for your child		
Acquisition/ gaining and employing of new strategies		
Sharing experiences		
Finding mutuality		
Using Humour		
Inspiration to hope		
Mentorship relationships		
Other:		

Any comment on above mentioned positive aspects?

.....

4.10 Did you experience some of the following negative aspects within the support group?

	Yes	No
Anticipation future challenges		
Disappointment in the group process		
One size fits all mentality of group members		
Friction between group members		
Jealousy over wellbeing of other group members		

Any comment on above mentioned negative aspects?

.....

4.11 Is there anything about the support group experience that you would change and/or recommend?

.....

**THANK YOU FOR PARTICIPATING!**

## ANNEXURE D

**SEMI GESTRUKTUREERDE VRAELYS  
UNIVERSITEIT VAN STELLENBOSCH  
DEPARTMENT MAATSKAPLIKE WERK  
ONDERHOUDSKEDULE**

**DIE GEBRUIKMAKING VAN ONDERSTEUNINGSGROEPE DEUR NIE-BIOLOGIESE VERSORGERS VAN  
KINDERS MET FASD**

**Al die informasie wat opgeneem is in hierdie onderhoud is vertroulik. Die sieninge en persoonlike informasie wat voorsien word deur die respondēt sal anoniem gehou word. Beantwoord die vrae so eerlik as moontlik asseblief.**

### **1 IDENTIFISERINGS BESONDERHEDE**

#### **1.1 Waar is u woonagtig?**

Informele Nedersetting	
Dorp of Stad	
Plaas	
Ander: _____	

#### **1.2 Hoe lank is u betrokke in 'n nie-biologiese versorger verhouding met die FASD kind-ers?**

Getal kinders	Tydsduur

#### **1.3 Wat is u verhouding tot die kind/ers?**

	Verhouding	Getal kinders
Aanneem ouer		
Pleegouer		
Grootouer		
Uitgebreide family		
Respyt (Rus sorg) versorger		
Ander: _____		

## 2 IMPLIKASIES VAN DIE FASD KIND/ERS?

2.1 Het u iets geweet van FASD voordat die betrokke kinders in u sorg geplaas is?

Ja	Nee
----	-----

Indien ja, wat het u geweet

.....

2.3 Hoe het dit u laat voel toe u uitvind die kinders is deur FASD geaffekteer?

Kwaad	
Angsbevange	
Ontkennend	
Bevrees	
Frustreerd	
Verdrietig	
Hulpeloos	
Ander: _____	

## 3 OMVANG VAN HOE DIE NIE-BIOLOGIESE VERSORGER GEAFFEKTEER WORD DEUR GEVOLGE VAN FASD

3.1 Ervaar u uitdagings in een of meer van die volgende areas?

	Ja	Nee
Opvoedkundige omgewing bekom vir die kinders		
Die kind betrokke hou in die gemeenskap		
Die huishouding aanpas vir die uniekie behoeftes van die kinders		
Handel met nuwe en aanhoudende gedragsprobleme		
Ander: _____		

Addisionele kommentaar: .....



## 3.2 Ondervind u die volgende implikasies?

	Ja	Nee
Emosionele konflik		
Aanhoudende terugslae		
Hoë vlakke van stress		
Uitputting		
Is u in staat om vir u self te sorg?		
Het u toegang tot rus sorg (respyt)?		
Struikel u om ondersteuning te bekom?		
Dink u aan die moontlikheid van virewig ouer-wees?		
Voel u ongewaardeer en vanselfsprekend aanvaar?		
Is u in staat om planne te maak en na te kom?		
Het u al droefheid/ verlies ervaar met betrekking tot u kinders se toekoms?		
Ervaar u vrees en hopeloosheid vir die toekoms van die kinders?		
Voel u geoordeel deur ander?		
Ander: _____		

Addisionele kommentaar: .....

3.3 Is u in staat om dienste te bekom wat u ondersteun in die versorging van die FASD kinders? (Medies, skolasies, sosiaal). Asseblief motiveer.

.....

3.4 Verstaan die betrokke maatskaplike werker/ster die geaffekteerde kinders, die kondisie en is hy/ sy in staat om toepaslike bystand/ ondersteuning aan u as versorger te bied? Asseblief motiveer U antwoord.

.....

3.5 Hoe word ander kinders en familie lede in die huishouding deur die FASD kinders geaffekteer? Asseblief motiveer u antwoord.

.....

3.6 Verstaan u uitgebreide familie en vriende FASD en is hulle in staat om u in die rol van nie-biologiese versorger te ondersteun?

.....

#### 4 DIE GEBRUIKMAKING EN ERVARING VAN 'N ONDERSTEUNINGSGROEP.

4.1 Benodig u ondersteuning in die versorging van die FASD kinders? Asseblief verduidelik.

.....

4.2 Voel u dat 'n ondersteuningsgroep 'n belangrike rol speel in die ondersteuning van nie- biologiese versorgers van FASD kinders? Hoekom?

.....

4.3 Hoeveel groep sessies het u bygewoon? \_\_\_\_\_

4.4 Hoe het die ondersteuningsgroep u as versorger gehelp om beter bekwaamd te wees in u rol as versorger?

.....

4.5 Het die groep sessies in u verwagtinge voldoen? Asseblief verduidelik

.....

4.6 Het u die volgende vorme van emosionele ondersteuning in die ondersteuningsgroep konteks ervaar?

4.6.1 Absolute respek and nie-veroordelende houding deur mede groepslede.

Ja	Nee
----	-----

Asseblief verduidelik

.....

4.6.2 Gedeelde/ wederkeurige verhoudings tot ander nie-biologiese versorgers.

Ja	Nee
----	-----

Asseblief verduidelik

.....

4.6.3 Normalisering van u omstandighede/ situasie.

Ja	Nee
----	-----

Asseblief verduidelik

.....

4.6.4 Instaatstelling van betekenisvolle emosionele vordering.

Ja	Nee
----	-----

Asseblief verduidelik

.....

4.7. Het u die volgende vorme van praktiese ondersteuning ervaar in die groep konteks?

4.7.1 Is u in staat gestel om u gedragspatrone met betrekking tot FASD te verander?

Ja	Nee
----	-----

Asseblief verduidelik

.....

4.7.2 'n Geleentheid vir rus.

Ja	Nee
----	-----

Asseblief verduidelik

.....

4.7.3 Die aaneensluiting van hulpmiddels in die groep.

Ja	Nee
----	-----

Asseblief verduidelik

.....

4.7.4 Was u in staat om in die groep konteks voorspraak te maak? (Groter pogings soos konferensies, bewusmakingsveldtogte, media projekte en navorsings projekte).

Ja	Nee
----	-----

Asseblief verduidelik

.....

4.7.5 Verandering/ verbetering en opleiding tussen groeplede.

Ja	Nee
----	-----

Asseblief verduidelik

.....

4.7.6 Het u praktiese hulpmiddels ontvang (soos skedules, roetines, tabelle, idees?)

Ja	Nee
----	-----

Asseblief verduidelik

.....

4.8 Benaderings in ondersteuningsgroepe

4.8.1 Het die ondersteuningsgroep u ondersteun met die gebruikmaking van u sterkpunte as versorger?

.....

4.8.2 Het u as deel van 'n gemeenskap gevoel in die ondersteuningsgroep?

.....

4.8.3 Het die groep werk sessies u geleer hoe om beheer van u eie gedrag te neem (doelgerigte gebruik van self?)

.....

4.8.4 Het u gevoel dat u waarde tot die groep kon bied?

.....

4.8.5 Was u in staat om te luister en te praat met u mede groepslede?

.....

4.8.6 Was daar ooit verbode/ taboe gesprekke opgebring en bespreek in jou groep? (Voorbeeld-  
- dissiplinêre metodes). Asseblief gee 'n voorbeeld.

.....

4.8.7 Voel u dat ander in 'dieslefde boot as u is' na u by die groep aangesluit het?

.....

4.8.8 Was daar geleenthede waar die ondersteuningsgroep u gehelp het om moeilike situasies in  
die gesig te staar en u gehelp het om met nuwe sieninge of strategies op te kom?

.....

4.8.9 Is u as individu nou beter in staat om probleme op te los?

.....

4.8.10 Was daar situasies waar herhaling/ repetisie/ rollespel plaas gevind het?

Ja	Nee
----	-----

4.8.11 Voel u dat u beter insig ontwikkel het en FASD beter verstaan na die bywoning van 'n  
ondersteuningsgroep?

.....

4.8.12 Was u voorsien met relevante informasie wat u kon toepas in die versorging met die  
geaffekteerde kind/ers?

.....

4.9 Het u van die volgende positiewe aspekte binne in die ondersteuningsgroep ervaar?

	Ja	Nee
Verbetering van begrip oor FASD		
Hulp om u kind beter te versorg		
Leer en uitvoering van nuwe strategieë		
Deel van u ervarings		
Gemeenskaplike belange		
Die gebruik van humor		
Inspirering tot hoop		
Mentor / leier verhoudings		
Ander:		

Enige kommentaar op die bogenoemde positiewe aspekte?

.....

4.10 Het u van die volgende negatiewe aspekte binne in die ondersteuningsgroep ervaar?

	Ja	Nee
Afwagting/ verwagting van toekomstige uitdagings		
Teleurstelling in die groepsproses		
‘Een grootte pas almal’ mentaliteit van groepslede		
Wrywing tussen groepslede		
Jaloesie oor die welbehae van ander groepslede		

Enige kommentaar op die bogenoemde negatiewe aspekte?

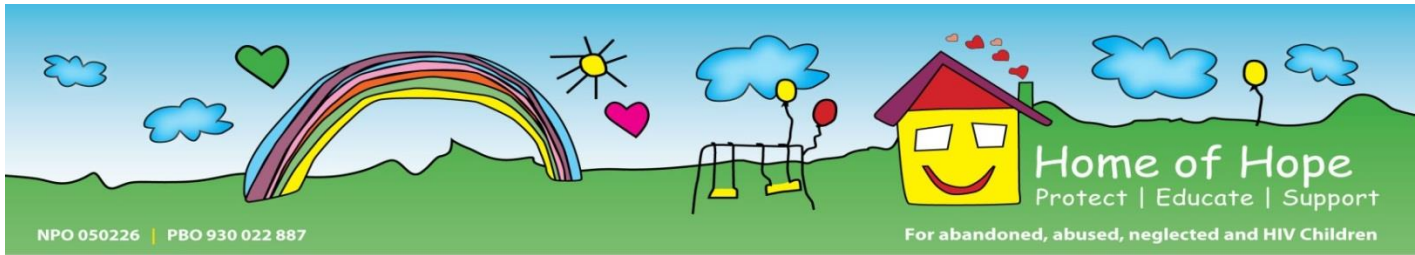
.....

4.11 Is daar iets wat u oor die ondersteuningsgroep ondervinding wil verander en/of voorstel?

.....

**DANKIE VIR U DEELNAME!**

## ANNEXURE E



11 April 2013

To whom it may concern:

**RE: Bianca Breytenbach- Master's Degree**

I confirm that Home of Hope gives Ms Bianca Breytenbach permission to conduct her studies at our organisation and gave her access to our service users (caregivers) as part of her Master's Degree.

Yours Truly

Eleanor Brook

CEO

Home of Hope